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A Pilot Study Exploring the Educational and Social/Emotional Benefits of Web-based  
Groups for Parents of Adolescents with Autism Spectrum Disorders

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A Dissertation

Presented to

the Faculty of the Morgridge College of Education

University of Denver

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In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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by

Eric T. Zimmerman

June 2013

Advisor: Dr. Karen Riley

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Author: Eric T. Zimmerman

Title: A pilot study exploring the educational and social/emotional benefits of web-based groups for parents of adolescents with autism spectrum disorders

Advisor: Dr. Karen Riley

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## **Abstract**

Research has indicated that parents of children with Autism Spectrum Disorders (ASDs) experience more feelings of isolation, depression and stress than those of children with other disorders including ADHD and Down Syndrome. While these feelings are especially elevated in parents living in rural communities who may have limited access to services, they are also present in those living in urban areas but are restricted due to challenges with childcare, transportation, finances and time. Furthermore, research posits that services for parents of the newly diagnosed or of younger children are abundant while services and education for parents of adolescents are hard to access regardless of location. This study explored the use of technology as a viable option for providing education and emotional support to parents of adolescents with ASDs and may assist in guiding future studies of this nature. Group sessions were facilitated remotely using video-conference technology and covered the topics of stress reduction, IEP's, puberty, and the transition to adulthood. This study employed a mixed methods design that utilized a concurrent triangulation approach. Within this approach, quantitative and qualitative data were collected concurrently and then compared to determine if there was convergence, differences, or some combination. The quantitative tools included, first, the Stress Index for Parents of Adolescents (SIPA) which was used to measure any change in stress levels that occurred throughout the treatment.

Pretest/posttest measures were then used to measure knowledge acquisition. The data gathered from these tools were then analyzed using a *t* test for paired samples. The qualitative phase employed a questionnaire that obtained anecdotal information regarding participants' experiences with and preferences towards parent groups; their feelings of depression, isolation, stress related to parenting a child with ASD; their confidence regarding the topics of stress reduction, IEP's, puberty, and the transition to adulthood; and their experiences within the web-based group setting. This qualitative information was used to look for themes to begin to understand how parents of adolescents with ASD may benefit from groups provided using Internet technology.

## Table of Contents

Chapter One: Introduction .....	1
Research Questions .....	10
Chapter Two: Review of the Literature .....	12
What is Autism Spectrum Disorder .....	12
Behaviors associated with autism and related disorders .....	14
History of autism and related disorders .....	15
Current prevalence rates .....	16
Parents' Experiences of Raising a Child with ASD.....	17
Profile of early childhood autism.....	17
Coping with the diagnosis of autism.....	19
Profile of school-age autism and beyond.....	24
The transition to school.....	25
Interventions for Children with ASD.....	32
Early childhood interventions .....	32
School-age interventions.....	34
The Long-Term Effects of Raising a Child with ASD .....	36
Parent Training.....	38
Parent education.....	39
Parent support .....	45
Factors affecting attendance .....	49
Distance Education .....	52
History of distance education.....	53
The Internet and its application to distance learning .....	54
Social support via the Internet .....	58
Parents of children with autism and theInternet .....	59
Considerations for using technology to education parents .....	60
Social presence.....	61
Telepresence .....	62
Conclusion.....	63
Chapter Three: Methods .....	64
Introduction.....	64
Research Questions.....	64
Research Design.....	66
Recruitment.....	68
Population and Sampling Procedures .....	69
Procedures.....	69
Group facilitation .....	69
Instrumentation .....	71
Data Analysis .....	75

Chapter Four: Results .....	76
Introduction.....	76
Participants.....	77
Quantitative Findings.....	79
Parent stress .....	79
Knowledge acquisition.....	81
Qualitative Findings.....	82
Pretreatment qualitative information .....	83
Posttreatment qualitative information.....	86
Conclusion .....	87
Chapter Five: Discussion .....	89
Introduction.....	89
Summary of the Study .....	89
Overview of the problem .....	89
Purpose statement and research questions .....	91
Overview of Results.....	92
Stress.....	92
Knowledge acquisition.....	96
Additional results.....	97
Limitations .....	99
Implications for Future Research.....	101
Conclusion .....	105
References.....	106
Appendix A.....	138
Appendix B .....	139
Appendix C .....	141
Appendix D.....	153
Appendix E .....	158
Appendix F.....	164

## **Chapter One: Introduction**

Over the last decade, the Center for Disease Control (CDC) has declared Autism Spectrum Disorders (ASDs) “...an urgent public health concern” due to the significant increase in prevalence. According to the 2012 CDC report, the prevalence of ASD has increased by 23% between 2009 and 2012, and 78% since their first report in 2007. It is now estimated that 1 in every 88 births results in the diagnosis (CDC, 2012). For every child affected by ASDs there are parents who are also impacted in a variety of ways. While parents can be trained to serve as vital service providers for their own child, the stress, depression, and anxiety experienced by parents of children with autism is higher than for parents of children with other disorders such as Down syndrome (Donovan 1988; Holroyd & McArthur 1976; Lee, Harrington, Louie, & Newschaffer, 2008). This stress can then impact their effectiveness as a parent and as a service provider. The psychological issues can be compounded by the age of the child and the location of the family, both of which significantly impact access to support services. The results of this study demonstrate the need for alternative methods to give parents of adolescents with autism access to services designed to educate and provide emotional support as they continue to support their child.



Autism Spectrum Disorders fall under the Pervasive Developmental Disorder umbrella in the American Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised (DSM-IV TR, 2000) and includes autism, Asperger Syndrome, atypical autism, Rett Syndrome, and Childhood Disintegrative Disorder. Each of these diagnoses is made up of a complex range of behaviors usually affecting communication and social functioning.

According to the literature, such as from the National Autism Center (NAC) and the DSM-IV, the behaviors or symptoms resulting from an ASD can include first, trouble with social development. For example, an infant may avoid touch or may not respond to his/her parents. As the child gets older, he/she may not engage in social interaction with others their age and struggle with understanding simple social cues making them appear “odd” to their peers. Second, communication can be significantly impacted. Children with an ASD can be completely nonverbal, may only “echo” the language of others, or simply may not understand the nuances of language, making it difficult for them to relate to or understand others in day-to-day communication. Next, individuals with autism or a related disorder may engage in repetitive behavior or have a restricted range of interests. For example, young children may “flap” their hands or rock back and forth. Older children may be obsessed with rules or interests (comic books, movies, sports statistics, etc.) to the point that it makes it difficult for them to function in environments where they need to focus on other topics, such as the classroom. The symptoms related to social, communication and restricted or repetitive interests and behaviors are considered to the core deficits. However, not only can these depend on age and change as the child ages,

there can be other behaviors associated with the disorder. These can include tantrums, anxiety, depression, sensitivity to light, sound, or touch; they may not understand social rules or boundaries in relation to sexual behavior; there may be difficulty with sleep causing issues with concentration and irritability; and the child may run away from their homes or schools causing issues with safety. The complexities associated with ASDs stem from the uniqueness of the disorder within each individual. There is a saying that, “If you’ve met one child with autism, you’ve met one child with autism.” This becomes difficult for clinicians, teachers, therapists, and especially the families that care for these individuals.

Parenting a child with an ASD is often a challenging journey, beginning with the diagnosis. In her book, *Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger’s Syndrome, Pervasive Developmental Disorder, and Other ASDs*, Chantal Sicile-Kira states:

The emotions that a parent goes through when raising a child with a chronic health need or disability, including ASD, has been likened to Kübler-Ross’s five stages of grief. The difference is that instead of going through each stage chronologically, parents are on a continual cycle, going through different stages at different times. They never graduate completely out of the grief cycle but do eventually learn to spend more time in the acceptance phase (p. 63).

Sicile-Kira goes on to explain that parents of children with ASDs and other disabilities grieve not because they lost their child but because they have lost the child they hoped for and dreamed about. Again, this grieving process never really ends as parents face new realizations throughout the life of their child. Parents may face the harsh reality that their child may never express love for them like other children; that they

may not develop friendships like other children; that they may never go to prom or college or get married and have children of their own; all are difficult to accept for parents with hopeful expectations.

Because the grief never ends, the psychological impact over time can be significant for parents of children with autism. Parents of children with an ASD face more psychological dysfunction due to the challenging behaviors associated with their child, such as tantrums, lack of pro-social behaviors, low adaptability, and resistance to change (Richman, Belmont, Kim, Slavin, & Hayner, 2009). These feelings of depression and anxiety are then exacerbated by the social isolation these parents feel as a result of not being able to attend religious services or other events for fear of being judged and rejected by other parents (Fox, Vaughn, Wyatte & Dunlap, 2002; Lee, Harrington, Louie, & Newschaffer, 2008). The more isolation these parents feel, the more they suffer from psychological stress, and the less they are able to care for their own child.

These feelings of isolation, grief, depression, and anxiety do not go away as the child with an ASD ages. In fact, the stress a family feels tends to hit its peak during adolescence (Donovan, 1988; Lee, Harrington, Louie, & Newschaffer, 2007). Research indicates that early intervention is important to the success of these children so, as a result, there are a vast array of programs and resources for parents of young children with autism. However, as the child gets older, the resources tend to become less (Twombly, Holtz & Daub-Sychra, 2011). Just as the resources disappear new challenges can arise. For instance, the child may become more aware of their disability, realizing that they are behind their peers developmentally and emotionally causing confusion and frustration

(Bashe & Kirby, 2005). Parents too realize this and feel more isolated. They also realize that their child may never be as independent as they once hoped requiring them to scramble for resources, causing more stress and frustration (Gray, 2002; Twombly, Holtz & Daub-Sychra, 2011). The behaviors adolescents with autism experience as a result of their confusion and frustration can take its toll on their parents. As the child reaches puberty, they can become more aggressive physically and sexually (Greenspan & Wieder, 2006), and can face more severe consequences for their behaviors (Bashe & Kirby, 2005). The bigger issue is that this is not isolated to a small population of families. According to the Organization for Autism Research, approximately one million people in the United States have received an ASD diagnosis, of which 80% are under the age of 22, meaning that many of these individuals are now entering their adolescent years suggesting a significant need for adolescent interventions (Sicile-Kira, 2011) and guidance for parents involved in providing these interventions.

Extensive research posits that parents play an important role as interventionists. Because parents are viewed as the experts on their children and their behaviors, their involvement in the treatment process and their collaboration with outside professionals is essential to the process (Briesmeister & Schaefer, 1998). This is why parent education continues to be the most commonly used tool in dealing with behavior issues in children (Carr, 1999; Griffin, Guerin, Sharry, & Drumm, 2010). Parent education programs are designed to impart knowledge of behavioral modification strategies and principles of learning theory (Briesmeister & Schaefer, 1998) and have become the most cost-effective way to assist children with ASD and their families (Anderson, Birkin, Seymour, &

Moore, 2005; Birkin, Anderson, Seymour & Moore, 2008; Engwall & McPherson, 2003; Frea & Hepburn, 1999; Howlin, 1981). Through parent education programs, parents of children with ASD not only gain valuable information regarding behavioral modification and increasing skill acquisition, they also receive social support in the process.

As mentioned above, parents of children with ASD suffer from significant stress and social isolation. Through education groups with others, participants can also obtain emotional support through the engagement with other parents experiencing similar issues to their own (Alat, 2006; Bull, 2003). Reliable information from professionals paired with social interaction with others who can empathize with what parents of children with ASD are going through, can lead to an increase in positive parenting practices (Connell, Sanders, & Markie-Dadds, 1997; Schultz, Schmidt & Stichter, 2011) which then benefits the child. While support from family and friends is important, research has found that one of the most powerful informal sources outside the family are other families of children with disabilities. When parents are able to share their experiences with other parents who are dealing with similar challenges, they benefit greatly from a decrease in isolation and stress (Kerr & Macintosh, 2000; Matloff & Zimmerman, 1996; Santelli, Turnbull & Higgins, 1997). However, for many parents of children with disabilities, there are factors that make it impossible to access these crucial services.

The factors affecting access and/or attendance in parent groups include geographical, financial, and logistical reasons (Kolb, 2007). First, geographically, autism and related disorders are not restricted to highly populated areas or those areas where services are plentiful, such as metropolitan cities. Children and parents in rural areas

have been referred to as being “double-disadvantaged” (Gething, 1997). This term is fitting considering the parents are dealing with an already difficult situation but are also impacted by the lack of, or limited quality of, services available to assist them (Doctoroff, 1995; Kolb, 2007). This has become an international issue in countries such as Poland and China, where services have not caught up to the numbers of children being diagnosed. A 2001 study in China revealed that 50% of children with disabilities did not receive any type of service. A majority of the children receiving services did so through their parents, who had little to no training. As a result, the parents reported being negatively impacted, both in their personal lives and in their careers, due to the lack of training and support (Wang, 2008).

Logistics and finances can play a major role in the attendance or access to parent groups. Finding child care for children with disabilities can be a difficult and expensive task (Kolb, 2007). Considering the behavioral, medical, and communication concerns, special consideration must be taken in deciding on a caregiver. If parents are required to drive long distances to access services, they must pay more for gasoline and may even need to take time off from work. This may be difficult for families of lower socioeconomic status (SES) categories. Research indicates that parents of lower categories are less likely to attend parent education groups (Cleve, 1989; Smith, Gabard, Dale, & Drucker, 1994) due possibly to their higher reliance on public resources such as Head Start (Rawlins & Horner, 1988; Smith, Gabard, Dale, & Drucker, 1994). Although the “gold-standard” continues to be face-to-face presentation of information and supports (Ritterband, Gonder-Frederick, Cox, Clifton, West & Borowitz, 2003) the lack of access

and attendance to face-to-face groups for many highlights the need for additional means of providing services.

For more than a century (Kiryakova, 2009), educators, psychologists, and other professionals have implemented various forms of distance learning programs using such technologies as letter writing (Davidson & Birmingham, 2001; Simpson, 2009), telephone (Lester, 1995; Simpson, 2009), email (Robinson & Serfaty, 2001; Simpson, 2009), radio, television, audio and video conferencing (Chute, Thompson, & Hancock, 1999). Distance education was originally designed to provide communication between teacher and student, who were in different places, at different times (Kiryakova 2009). However, with rapid changes in technology, distance education has moved from simple “correspondence” (Aggarwal, 2000) to providing the experience of being in the same place, at the same time.

The Internet has provided a forum for immediate communication feedback through email and websites. This has led to an increase in social communities that not only provide information but support as well. These “communities” are made up of strangers who then provide a sense of belonging (Scharer, 2005) and emotional support often found in traditional face-to-face learning environments. For example, in a study of email messages posted by individuals with physical disabilities within an online support group, Braithwaite et al (1999) found that emotional *and* informational messages were offered more than any other type of message. Again, this is often found in the traditional classroom environment as well. Parents of children with autism have also found this medium to be a valuable resource. Although the study of parents of children with autism

and their use of the Internet is still relatively new, there is evidence that parents have begun to use it to discuss their challenges and to connect with other parents, through listservs, dealing with similar issues, therefore creating virtual support environments (Fleischmann, 2005; Huws, Jones & Ingledew, 2001). However, there continue to be concerns about online support groups as compared to the “gold standard” of face-to-face communication.

Issues that continue to arise among computer-mediated groups include feeling socially disconnected (Haefner, 2000; Menchaca & Bekele, 2008; Reisetter & Boris, 2004; Slagter van Tryon, & Bishop, 2009), lower levels of trust with the information that is being presented or “posted” (Coulson & Knibb, 2007), the high incidence of negative messages being sent to participants, concerns with confidentiality (Kane & Sands, 1998; Sands, 1999; Scharer, 2005 Robinson, Patrick, Eng & Gustafson, 1998), and the misunderstandings that can occur without the presence of facial cues or voice inflection (Scharer, 2005). This lack of social presence is what deters some from engaging in computer-mediated support, thus continuing to isolate those who need the information and support the most.

Social presence in today’s technologically advanced world refers to the awareness of others by “...cognitive and affective engagement in computer-mediated social spaces” (Shen & Khalifa 2008). One specific technology that is providing this social presence through a computer-based medium is telepresence. Telepresence technology is one form of enhanced videoconference technology (Engebretson, 2010) that can allow others to meet face-to-face without being in the same room. To date, the technology has been



primarily used in the business sector allowing for meetings to occur while eliminating the need for travel. However, other professions are beginning to see the value in such technology (Engebretson, 2010) as it allows for access to immediate information, language translation, and secretarial services, making conferencing, learning, and training easier and more efficient (Walker, & Shepard, 1999). What is not known is whether or not the use of technology, such as TelePresence, can be used as a viable option in providing educational and emotional support to parents of adolescents with ASDs when access to face-to-face groups is not an option.

### **Research Questions**

These research questions were developed after an extensive literature review which indicated a need for additional research into viable options for providing training and emotional support to parents and children of adolescents with autism and related disorders. Furthermore, these questions are based on research which suggests videoconference technology can be a viable option. However, research on such technology outside of the business and educational environments is limited.

1. What is the effect, based on quantitative measures, of web-based groups on their ability to
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?

- b. Decrease stress by providing social and emotional support to parents of adolescents with autism or a related disorder, as measured by a pre and post stress inventory?
- 2. What is the effect, based on qualitative information, of web-based groups on their ability to
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?
  - b. Decrease stress by providing social and emotional support, to parents of adolescents with autism or a related disorder?

The answers to these questions will determine if the use of videoconference technology in place of the traditional face-to-face groups can be effective in providing education and social/emotional support to parents of adolescents with an ASD.

## **Chapter Two: Review of the Literature**

To better understand the diagnosis of Autism Spectrum Disorders (ASD), a brief description of the diagnostic criteria are given along with related disorders that fall under the same classification of Pervasive Developmental Disorders (PDD). By reviewing this information, one can see the complexities involved in such a diagnosis which often causes confusion and grief in the parents of children diagnosed with ASD.

### **What is Autism Spectrum Disorder?**

According to the American Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised (DSM-IV TR, 2000), Pervasive Developmental Disorder (PDD) encompasses autistic disorder, Asperger Syndrome, atypical autism, Rett Syndrome, and Childhood Disintegrative Disorder, all of which are associated with developmental delays in socialization and communication skills. Although similar, there are differences among the different disorders. In order for a child to be diagnosed with ASD, individuals must exhibit “abnormal functioning” in at least one of the following areas: 1. social interaction, 2. language as used in social communication, and 3. symbolic or imaginative play. These three core elements make up what is known as Wing’s Triade (Perez, Gonzalez, Comi, & Nieto, 2007; Wing & Gould, 1979). Another dominant feature is the engagement in repetitive and stereotyped behaviors (Bitsika, 2008; Frith, 1991; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999; Wing & Gould, 1979), such as wringing of hands, clapping, rocking of bodies and/or snapping of fingers (DSM-

IV TR, 2000; Linares-Gonzalez, 2006). Although these characteristics appear straightforward, what makes ASD intriguing yet challenging to researchers, parents, and teachers is the significant between-child and within-child variability (Bitsika, 2008; Howlin & Moore, 1997). This variability is what constitutes the “spectrum” or continuum nature of the disability that ranges from “low” to “high” in relation to an individual’s behavioral, social/emotional, and educational functioning (Bitsika, 2008; Starr, Szatmari, Bryson, & Zwaigenbaum, 2003). The differentiating factor between autism and Asperger Syndrome lies in the severity. Many professionals consider Asperger Syndrome to be a “milder” form of autism as children affected by Asperger Syndrome may have adequate language and cognitive abilities but struggle socially (Autism Society). Childhood Disintegrative Disorder (CDD) is characterized by normal development until the age of 2 to 4 years at which time there is a loss in language, social, play, motor, and toileting skills (Wilkinson, 2010). According to the Mayo Clinic, CDD is similar to ASD but differs in regards to a more “dramatic loss of skills” (Mayo Clinic Staff, 2010). Rett Syndrome occurs exclusively in girls and is characterized by diminished physical and communication skills over time. In the initial stages, the child might display “autistic-like” behaviors, leading to its classification under PDD (Wilkinson, 2010).

According to the American Psychological Association (APA), after discovering that ASD results from problems with neurological development, researchers have developed medical, educational, and behavioral approaches to treatment (American Psychological Association, 2000). Since there is no medical cure for ASD, medical

treatment options are those that utilize medications to help minimize symptoms of ASDs. For example, medications may be helpful in reducing seizure activity, hyperactivity, or issues related to anxiety. Because medications by themselves are not effective in changing behavior, behavioral interventions become an important part of the treatment regimen. This may include techniques that reward for good behavior and punish for inappropriate behavior. This type of behavior management can be helpful in increasing communication and social interaction while decreasing self-injurious and aggressive behaviors. In the educational environment, social skills training and integration into the regular classroom can be forms of intervention where modeling of appropriate behaviors can occur.

#### **Behaviors associated with autism and related disorders.**

The between-child variability that can exist among those with ASD can include sensory processing disorders, hyperactivity, short attention span, impulsivity, violence towards others, self-injurious behavior, high pain thresholds, sleep and eating disorders, and significantly limited or excessive fears (Benderix, Nordstrom, & Sivberg, 2006). The combination of a cognitive disability (CD) and an ASD presents greater risk for developing challenging behaviors such as those listed above (Bodfish et al., 2000; Rojahn, Wilkins, Matson, & Boisjoli, 2009). Additionally, research indicates that the presence of maladaptive behaviors can inhibit the treatment of the core symptoms and can negatively affect the trajectory towards independence (Matson & Nebel-Schwalm, 2007; Rojahn, Wilkins, Matson & Boisjoli, 2009). Various studies conclude that rates of psychiatric comorbidity in individuals with ASD can range from 41% to 81%. These

psychiatric conditions include social anxiety, phobias, depression, obsessive compulsive disorder (OCD), and attention deficit/hyperactivity disorder (ADHD; Hess, Matson, & Dixon, 2010; Steyn & Le Couteur, 2003). Further findings within these studies suggest that those who are “high” on the spectrum, or high-functioning autism, are aware of their disorder and, as a result, are at a higher risk for depression (Hess, Matson, & Dixon, 2010; Volkmar & Klin, 2005). The challenging behaviors associated with ASD, and with its comorbid psychiatric conditions, are strongly correlated with the quality of life for the diagnosed child and his/her family (Buschbacher & Fox, 2003; Hastings & Brown, 2002; Matson & Minshawi, 2006; Matson, Wilkins, & Macken, 2009; Plant & Sanders, 2007). Social and educational opportunities in and around the community may be limited due to safety issues related to violent and self-injurious behaviors (Matson, Wilkins, & Macken, 2009; Sigafos, Arthur, & O’Reilly, 2003), and families may not engage with others socially for fear of being embarrassed when their child has an outburst (Collier & Reid, 2003; Fox, Dunlap, & Buschbacher, 2000).

### **History of autism and Aspergers.**

The word “autism” stems from the Greek word “autos” meaning self and was first used in 1911 by Swiss psychiatrist Eugen Bleuler (Williams, 2000). He used the word “autism” to describe the “social alienation” associated with negative symptoms of individuals with schizophrenia (Rapin & Tuchman, 2006). In 1943, Dr. Leo Kanner borrowed the word to describe the behaviors of children previously thought to have mental retardation. During a case study of 11 children, Kanner noted that these children displayed common behaviors, such as limited social interaction, speech delays, ritualized

and/or repetitive behaviors, difficulty with transitions, and regression of previous acquired skills (NAC). Kanner then wrote a paper titled “Autistic disturbances of affective contact,” and referred to the common characteristics of the children as a “unique ‘syndrome’ not heretofore reported” (Williams, 2000). In 1944, pediatrician Hans Asperger studied a group of children and noted social deficits similar to those found in Kanner’s study. However, there were notable differences in their cognitive and language development compared to the children in Kanner’s study. Asperger’s group was reported as being very bright and displayed adequate language and adaptive functioning skills. It wasn’t until three decades later that Asperger’s study reemerged and changed how autism was viewed and how it was diagnosed.

#### **Current prevalence rates.**

One reason ASD receives so much attention is the current prevalence rate. According to the Centers for Disease Control and Prevention, 1 in 88 children has been diagnosed with autism or a related disorder. The report also stated that the rate of incidence was 5 times higher in boys than in girls. Since the last report in 2009, the biggest increase occurred in Hispanic children (110%) and African American children (91%; CDC, 2012). Additionally, the Autism Society of America estimates the growth rate to be at 1,148%, making it the fastest growing developmental disability, and researchers approximated that 1 out of 760 children in China under the age of 14 have the diagnosis (Huang, 2003; Wang, 2008). Mori et al., (2009) estimated that 21.1 Japanese children out of every 10,000 have autism. These authors suggest that the prevalence of Asperger’s syndrome is higher, citing one Canadian study that estimated 50% of children

with Asperger's are not diagnosed until adulthood (Howlin & Asgharian, 1999; Mori, et al., 2009).

ASD is a life-long disability with varying challenges along the way. Parents bear much of the responsibility of assisting the child through these challenges. As such, the experiences of these parents demonstrate how pervasive and far-reaching the disorder can be, not only for those diagnosed, but for those who care for them.

### **Parents' Experiences of Raising a Child with ASD**

Raising a child is a difficult job regardless of whether or not the child has a disability. For parents of a child with a disability, they are confronted with extra fears, challenges, and burdens that can overwhelm the entire family system. According to the National Autism Center (NAC), these challenges evolve depending on the developmental stage causing confusion and frustration for the family. Below is a section containing information on the profiles of children through the ages and the experiences of their parents as they pass through the varying stages. The information contains quotes, when possible, as it provides powerful insight into very personal experiences. Parents' actual words are used as not to lose meaning by interpreting what they are attempting to say. For the purposes of this paper, early childhood refers to children not yet in the school system. School-aged children are considered those who have entered kindergarten.

#### **Profile of early childhood autism.**

Prior to getting a diagnosis, parents may observe behaviors in their child that may raise concerns over their well-being and/or development. Such behaviors have been well documented and are charted below. It should be noted that because of the "spectrum"



nature of the disorder, this list does not apply to all persons with autism. The behaviors listed in Table 1 are behaviors often seen with this particular population.

Table 1

*Behaviors of Young Children with Autism Spectrum Disorders*

---

**Social Development**

- May avoid touch
  - May isolate from groups
  - An infant may not imitate facial expressions
  - Toddlers may not laugh in response to parent's laughter
  - Failure to respond to the emotional needs of others
- 

**Communication Development**

- May lack speech
  - Immediate or delayed echoing of other's words
  - Use of scripted phrases
  - May not respond to name
  - Unlikely to use gestures
- 

**Restricted, Repetitive, Nonfunctional Patterns of Behavior**

- Repetitive motor movements like hand-flapping, finger flicking, rocking, etc
  - May line up toys for visual examination
  - May categorize toys instead of playing functionally with them
  - Some rigidity in routines
- 

**Other**

- Tantrums
  - Sensitivity to light or sound
  - Feeding challenges (often associated with texture)
  - Safety concerns (e.g., may run outside in bare feet into the snow)
- 

*Note.* Adapted from *Evidence-Based Practice and Autism in the Schools* by the National Autism Center – NAC, 2009, p. 26. Copyright 2009 by the National Autism Center.

If the parent continues to have concerns regarding his/her child's development, an assessment process may be employed by various professionals such as pediatricians, psychologists, and psychiatrists. Components to the assessment process may include verbal reports, direct observations, direct interaction and evaluation, and third-party reports (Shriver, Allen & Matthews, 1999; Wilkinson, 2010, Filipek et al, 1999). It is recommended that a comprehensive developmental assessment approach be implemented which consists of a variety of tools and methods that continue over a period of time (Wilkinson, 2010)

### **Coping with the diagnosis of ASD.**

When a child is first diagnosed, parents can go through a range of emotions such as shock, sadness, anger and grief related to the loss of their idealized child ([www.autismspeaks.org](http://www.autismspeaks.org)). Laura Anderson, author of *Accidentally Beautiful: The Collective Wit and Wisdom of Autism and ADHD*, recalled the moment when her son, Justin, was diagnosed:

The therapist delivered the news and I sat quietly, watching my life swirl around before my eyes and change into something I didn't recognize. I remember feeling like there was no air to breathe. There was a buzzing in my ears and tingly little lights dancing in my vision. I remember my mouth failing to make a sound and my brain being unwilling to help me form thoughts. My world swam around in my head while I watched Justin line up the trains he loved so dearly...I was scared. I cried. I swore. I got angry at God. I pleaded. I prayed...I asked for answers that didn't exist...I felt alone in my grief (p. 6).

According to some, death and divorce are the most stressful events anyone will face during their life. However, according to Ann Boushey, a parent of a child with ASD and author of "The Grief Cycle – One Parent's Trip Around":

I believe that there is a third event just as distressing devastating as divorce and death. It is only coincidental that this word also begins with *d*. The word is *disability*. Having a child with a disability is every parent's nightmare (p. 27).

Grief is a personal endeavor and can look different for everyone and varying cycles can be found in literature. However, there are some common elements including shock, anger, denial, bargaining and acceptance. Boushey provides another cycle, described below, which includes some of the common elements but also some new ones that are perhaps unique to parents of children with ASD. Since grief is an individual process, quotes, rather than just definitions, are provided to give personal insight into what it means to be in any given stage.

1. Shock –

It's the same when you hear of a loved one dying, or when your spouse tells you he or she wants a divorce. Things become blurry after this devastating news. You continue to function, but you don't know how you do it or later remember the details (Boushey, 2001, p. 28).

This stage for some is not as significant as it is for others. For parents of children with atypical development from birth, this stage may be fairly minor or short lived. However, for children who may have regressed or who have above average skills in several areas while having deficits in others, this stage can be difficult.

2. Denial – The second stage according to Boushey is denial. During this stage, many parents may have received the diagnosis for their child, but choose not to accept it.

They may ignore it or may seek the advice of other professionals.

3. Guilt – “This guilt was the feeling that I had done something during pregnancy or during the developmental years of my child's life that had caused his autism”

(Boushey, 2001, p. 29). In the early years of the study of ASD, many thought that the disorder was a result of poor parenting. In 1944, Bruno Bettelheim, director of the Ortho-genic School for Children with Emotional problems, which specialized in children with ASD, stated that autism was the result of being raised in “unstimulating environments” and due to parents being “unresponsive” to their children (Williams, 2000). In recent years, research has revealed that parenting is not the cause of autism but parents continue to feel guilt especially considering a specific cause has not been identified (Boushey, 2001).

4. Isolation – “I was not only a mother with the normal cares and worries of a mother, but also a mother of a child with a disability. No one could understand what I was going through except another mom of a child with a disability” (Boushey, 2001, p. 29). Boushey goes on to say that due to the lack of interest her son had in others; this limited her opportunity to connect with others as well. Some parents not only feel isolated from the outside world, but also within their own environment as well. Laura Anderson describes how her relationship with her husband changed, leaving her isolated in her own home.

Every day started and ended without Brett. He seemed to have a pretty easy gig if you ask me. At work he would sit in a room alone surrounded by high-tech equipment, an endless supply of coffee, and a state-of-the-art sound system to keep him company. He worked late but came home to a quiet house...Brett reminded me that he wasn't running out on the evenings' demands because he was going to work to support his family. I knew this, of course, but somehow I still resented that I was always the only one of us who ever had to attend to all these needs (Anderson, 2010, p. 12).

## 5. Panic –

No matter how much I read on the subject, I felt behind. No matter how many conferences on autism that I attended, it wasn't enough. My son was growing up right before my eyes, and I felt that every step he took forward, I needed to take two to stay caught up" (Boushey, 2001, p. 29).

This stage can impact parents in numerous realms of their lives. Anderson describes her panic during the pregnancy of her second child.

A terrifying realization rose up and it dawned on me that Aaron too, may be on the spectrum. I was already 6 months along when Justin was diagnosed. I was already well on my way to an even more complicated future (Anderson, 2010, p. 8).

## 6. Anger – "You are angry at the world, yourself, your spouse, perhaps even at God.

Many parents go through this when their child is diagnosed, because life is not fair" (Boushey, 2001, p. 29).

## 7. Bargaining – This is the stage where parents begin to look for solutions to the problem, rational and irrational. Some parents think that if they would just do something different like change their child's diet, therapy, or doctor, everything will "go away". Unfortunately, there is no cure for autism so this can be a frustrating step in the process.

## 8. Acceptance and Hope – The final stage is where parents realize that, although symptoms can improve with appropriate interventions, the autism will never disappear completely. "Yes, I accept that my child has autism and will always have autism, but that doesn't mean we are without hope" (Boushey, 2001, p. 29). This final step is perhaps the most difficult to get to but also the most important. "The process

of coming to terms with a diagnosis for one's child, that is, accepting and feeling resolved with respect to it, is a daunting challenge for most parents" (Milshtein, Yirmiya, Oppenheim, Koren-Karie & Levi, 2010, p. 89). Parents must let go of their idealized child and accept the reality that they have a child with a disability. "Being resolved has important implications for the well-being of the child and for the parent" (Milshtein, Yirmiya, Oppenheim, Koren-Karie & Levi, 2010, p. 89).

The time immediately post-diagnosis can be a turbulent time as parents begin to learn about their child and what it is like to live with ASD. As the children embark into the educational system, first through preschool, new challenges emerge. One parent described the chaos she experienced during the preschool years.

But preschool only seemed to amplify the visible differences between him and his peers. My son had developed a nasty biting habit, which I later realized was his means of communicating pain or frustration. He had bitten me several times, but when he bit his aide at preschool, I lost it: Suddenly, I started to worry constantly about him. I felt overwhelmed by the physical demands of caring for my child (not to mention my home). Patrick was like Looney Tunes' Tasmanian Devil...on speed. He was destructive and wild, and by the time I wrapped my head around what it would take to clean up one mess, like an entire gallon of milk spilled into the couch cushions, he was on to his next feat, like dumping a canister of flour on the floor so that he could watch the dust billow in the sunlight. Once he urinated into a DVD player and nearly set the house on fire. And all of this would happen while my back was turned, while I was going to the bathroom, trying to clean, do laundry, or, heaven forbid, answer the phone. I could never, ever let my guard down, and by the end of the day, I was exhausted (Brodey, 2007, p. 64)

Judith Grossman of the Ackerman Institute recommends a variety of ways to cope with the diagnosis of ASD, and the ensuing behaviors, including taking time to heal, writing in a journal, beginning treatment for the child as soon as possible, learning the facts related to autism, talking about their feelings, learning to appreciate the gifts the

child does offer, and joining a support group ([www.autismspeaks.org](http://www.autismspeaks.org)). These feelings do not necessarily go away as the child becomes older; they just change as the child's needs change.

### **The profile of school-age autism and beyond.**

Table 2 provides a list of behaviors developed by the NAC designed to succinctly describe autism in the school-aged child and into adolescence. Again, it should be noted that because of the “spectrum” nature of the disorder, this list does not apply to all persons with autism. The behaviors listed here are behaviors often seen with this particular population.

Table 2

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#### *Behaviors of School-Aged and Adolescents with Autism Spectrum Disorders*

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##### **Social Development**

- **Early School Years**
    - May not engage in social games
    - May prefer younger children
    - May appear “bossy” when playing with other children
  - **Adolescence/Early Adulthood**
    - Gaps in social skills become even more apparent
    - Dating challenges
    - Social challenges sometimes related to issues such as poor hygiene
- 

##### **Communication Development**

- **Early School Years**
  - May sound like “little professors” who are lecturing on a topic
  - Conversations are one-sided
  - May not see how their behavior hurts others
- **Adolescence/Early Adulthood**
  - Poor understanding of abstract concepts
  - Challenges in understanding jokes or slang

Table 2 (continued)

- May mimic language from television or movies, placing them at risk for problems at school (e.g., say “I’m going to get a gun and dill him” as a means of expressing anger or frustration)
- 

**Restricted, Repetitive, Nonfunctional Patterns of Behavior**

- **Early School Years**
    - Rule-bound
    - May create own rules to make sense of the world – then have a hard time managing when others violate these rules
  - **Adolescence/Early Adulthood**
    - May engage in elaborate rituals to avoid motor tics
    - May obsess for hours about a brief encounter with a peer
- 

**Other**

- **Early School Years**
    - Academic concerns
    - Difficulties with concentration and irritability due to sleep or communication problems
    - May be disruptive during transitions
    - May be clumsy in sports activities
  - **Adolescence/Early Adulthood**
    - Symptoms of depression or anxiety
    - Acting out
    - May not understand rules regarding sexual behavior (and may be set up by peers to violate these rules)
    - Increased risk for seizures (associated with onset of puberty)
- 

*Note.* Adapted from *Evidence-Based Practice and Autism in the Schools* by the National Autism Center – NAC, 2009, p. 26. Copyright 2009 by the National Autism Center.

**The transition to school.**

A review of the literature revealed that there is limited documentation with regard to parent interviews and quotes from parents of school-aged children and adolescents with ASD. Furthermore, there appears to be a lack of information available to help parents of school-age children with ASD (Bashe & Kirby, 2005 p. 441). However, due to



the growing number of children with ASD in the school system, this is clearly becoming an area of focus for researchers as there is a significant need to assist parents and other care-givers when dealing with the ever-changing complexities of ASD in school-aged children, through their adolescence and beyond.

As children with ASD enter school, parents express a variety of concerns and must face multiple challenges. Those concerns include learning difficulties, being bullied, and achieving in the academic environment (Lee, Harrington, Louie, & Newschaffer, 2007). Right from the very beginning, the children and their parents are faced with the daunting experience of transitioning out of the small environment of preschool into the larger environment of kindergarten. The transition from preschool to kindergarten is seen as the first educational transition and proves to be an important step for the child and their family (Forest, Horner, Lewis-Palmer & Todd, 2004; Wolery, 1997). One mother describes the preparation it took to get her daughter ready for this transition.

I reminded myself daily we had done all the right things; Lauren met her new teachers and was attending speech and occupational therapies in her new school. She attended a preschool once a week during the summer to prep her for the social aspects of being around other children. We played at the school playground to make it a familiar place for her.

Although they prepared, Lauren's mom still worried.

I worried that she might regress with the overwhelming options and stimulation school offered. I worried she would withdraw; that the other kids would reject her. I worried she would react with aggression and she would be asked to leave the class. I worried she would escape. I worried she was too young for school all together...I realized the amount of school was "too much" for one person – me (Osterman-API, 2006, p. 52).

Transitions can be particularly difficult for children with ASD due to their difficulties with communication, problem-solving and adaptive skills (McIntyre, Blacher & Baker, 2006; Quintero & McIntyre, 2011). Transitions often involve shifts in services causing children to encounter cognitive and behavioral problems (Emerson, 2003; McIntyre, 2008; Quintero & McIntyre, 2011). Parents are also affected by transitions and report more transition-related concerns than parents of typically developing children (McIntyre, Eckert, Fiese, DiGennaro & Wildenger, 2010; Quintero & McIntyre, 2011). Parents must continue to implement previously learned interventions and teach new communication and social skills all in the new context of school.

Once children reach school, this is the time when their ASD symptoms, good and bad, may become more apparent and visible to others (Bashe & Kirby, 2005). Some children with special interests or areas where they excel may do rather well in some academic environments. Others who display more of the negative symptomology may find the school environment to be especially difficult. Bashe and Kirby (2005), state that schools by design can be “hell” or “torture” for children with ASD. The amount of children in a school, the number of transitions throughout the day, the noise, and numerous social situations students have to navigate during the day, can cause children with ASD high levels of stress. This stress combined with other conditions such as OCD, depression, and anxiety can cause “serious problems. If not already present, the authors state that the stress can even cause psychiatric conditions including depression, OCD and anxiety. Some adults with ASD have reported that they suffer from posttraumatic stress disorder (PTSD) as a result of the social failure, bullying, and other emotional stress

endured during their school years (Bashe & Kirby, 2005). Parents are not immune to the turmoil during the school years. Some students are able to maintain throughout the school day but melt down as soon as they get home (Bashe & Kirby, 2005). Parents are then left to deal with the emotional and behavioral manifestations of the daily stress.

Not only do parents have to be concerned with what happens socially throughout the day, they need to be concerned with the current state of the educational system. With the number of children entering the school system with the ASD diagnosis, there is an increased need for services. Budgetary constraints are making it difficult to hire trained professionals, to train existing staff, or to buy necessary curriculum and equipment, all to properly service students with ASD (Sicile-Kira, 2004).

Then, as the child enters adolescence, evidence suggests this is the time that the family experiences the greatest amount of stress (Donovan, 1988; Lee, Harrington, Louie, & Newschaffer, 2007). “One day you realize that the boy who learned to ride a two-wheeler at age eleven and still has difficulty holding his fork properly is starting to grow facial hair” (Bashe & Kirby, 2005, p. 440). Evidence suggests that puberty can bring new challenges to an already difficult situation.

Fourteen-year-old Tony, a good-natured boy with Asperger’s Syndrome, was doing fairly well in a regular classroom setting. However, as he began to go through puberty, Tony started to have more difficulties with making simple decisions: he often froze up when asked to choose between playing a game inside or going outside. He was also relying more on scripted language in new social situations and was also becoming much more negative. Tony’s parents wondered if these behaviors were typical of puberty or if their son was regressing developmentally (Greenspan & Wieder, 2006, p. 212).

Although children with ASD hit puberty at the same time as their typical developing peers, they may be behind emotionally and developmentally adding to the confusion for

the children themselves and their parents (Bashe & Kirby, 2005). Jeremy, a young adult with autism, describes what it was like going through his pubescent years with his limited communication skills and difficulties he and his family faced.

I had a difficult time when I came into the teen years. I tried to tell my mom (nicely!) but I had no way to communicate this. So I tried to tell her by redecorating the house. It lasted about a year, during which I frequently pulled down all the books off the bookshelves because I was trying to tell her that I wasn't understanding the great differences felt all over my body. Usually my nice mom understood the things I did, but these great trials I put her through frankly did not make her understand really the great difficulties I was going through. One day my body felt better again, but it took some getting used to. I remember nicely my parents moved all the book cases and books into the garage out of my reach. Then I tried to find them, but couldn't so I just rearranged my room. It was really frustrating that my mom did not understand (Sicile-Kira, 2011, p. 40).

The inability to express their confusion with the changes teens face combined with developing sexual interests and increased levels of aggression can be a dangerous combination. Adolescents will develop physically, including increased size and strength, but may not have the processing abilities to affectively problem solve in difficult situations. This may lead to increased aggression and sexual acting out towards others without the full understanding of society's rules against such behaviors (Greenspan & Wieder, 2006). This causes issues for adolescents with ASD as they face harsher penalties for such behavior but are often times without less support and guidance (Bashe & Kirby, 2001). Parents may request help but may face challenges simply because of their child's age. The assistance available for parents at this age may be somewhat limited as resources currently focus primarily on early intervention which occurs in the early years. However, according to the Organization for Autism Research, about one million people in the United States have received an ASD diagnosis, of which 80 percent

are under the age of 22. Many of these individuals are now entering their adolescent years suggesting a significant need for adolescent interventions (Organization for Autism Research, 2009; Sicile-Kira, 2011).

Unfortunately, there is a belief by some, even professionals in the field, that children will not improve behaviorally once they reach adolescence. Research has indicated that this simply is not true and that professionals should continue working on building developmentally appropriate skills and behaviors (Greenspan & Wieder, 2006).

At this point, independence becomes an important issue as children tend to remain more dependent upon their families or services as compared to others with differing types of disabilities or medical conditions (Ballaban-Gil et al., 1996; Howlin et al., 2004; Lee, Harrington, Louie, & Newschaffer, 2007; Seltzer et al., 2004). However, this can prove to be difficult for the adolescent as well as the parent due to the paradoxical nature of the situation for teens with ASD. Teens want to be more independent but this can cause fear and anxiety for those with ASD making them apprehensive to be more independent. Additionally, friends, teachers, and parents may place higher demands on the teen, as is usual for the typical teen, but the teen with ASD may not be able to handle this new found responsibility. With all of the internal conflict of wanting to be independent but not really knowing how, the teen with ASD is therefore more likely to develop oppositional behaviors. Conversely, parents, teachers, and friends may lessen their expectations of the teen due to their ASD. The teen can then respond defiantly in an effort to communicate their frustration with the limits placed on them (Greenspan & Wieder, 2006).

Not only are parents left to deal with the behaviors associated with raising a teen with ASD, they are confronted with an increased financial burden as well. According to the ASA, the cost of caring for an individual with autism over a lifetime is on average 3.2 million dollars. This financial burden and the higher rates in work loss for parents of children with a disability (Hecimovic & Gregory, 2005; Lee, Harrington, Louie, & Newschaffer, 2007; Parish et al., 2004; Swensen et al., 2003), place these parents at higher risk for physical and psychological distress (Allik et al., 2006; Baker et al., 2002; Bromley et al., 2004; Fombonne et al., 2001; Klassen et al., 2004; Lee, Harrington, Louie, & Newschaffer, 2007).

As stated earlier, parents of children with ASD struggle with the initial diagnosis but are able to accept the disability, after going through the grief process. The diagnostic period is just the first of many situations when parent go through the grief process. Once adolescents reach the age at which they would normally become independent, parents can again experience grief over this step in their child's life. For some, the adolescent years can bring about feelings of "not fitting in" with other parents of neurotypical children (Bashe & Kirby, 2001). These parents must face acceptance around the difficulties related to ASD and adulthood. Over 60% of children diagnosed with ASD have demonstrated poor outcomes regarding social interaction, communication, and restricted interests later into adulthood (Billstedt, Gillberg & Gillberg, 2005; Eaves & Ho 2008; Paul, 1997; Matson et al., 2010). Data also suggests that due to the lifelong nature of the disorder, continual monitoring and assessment is necessary (Matson et al., 2010).

Again, once the child reaches adolescence, the guidance parents receive can be limited. This can become more difficult as the adolescent reaches adulthood. Fortunately, with a strong foundation during the years when support is available, parents may have the skills to assist their children as they reach adulthood.

## **Interventions**

### **Early childhood interventions.**

Research indicates that one of the keys to successful intervention is providing it early in the child's development (Ben-Itzhak, Lahat, Burgin, & Zachor, 2008; Ingersoll, Schreibman, & Stahmer, 2001; Matson, Mahan, & Matson, 2009; Matson & Smith, 2008). Early interventions promote the creation and maintenance of an environment that provides early enrichment and the foundation for intensive interventions that assist in the development of the child. Additionally, children encounter greater success in learning to generalize across environments such as home and school (Rocha, Schreibman, & Stahmer, 2007; Schreibman & Koegel, 1996). According to Early Intervention Colorado (EIC), early intervention is necessary as the first three years of life have proven to be a pivotal time in learning and development. EIC also states that this early intervention may decrease problems later in the child's life and recommends that families of children with disabilities, ages birth to two years, follow a series of steps to ensure that they receive the proper care during this critical time of development. These steps include:

1. A referral for services. This step allows families who may be concerned about the development of their child the opportunity to have their child evaluated if it is deemed necessary. Parents also have the opportunity to ask questions and seek

advice as to what steps are next, regardless of whether or not an evaluation is completed.

2. A screening to determine how the child is developing and learning. This snapshot of the child's development provides guidance as to what services/evaluations may be necessary.
3. Development of a relationship with a "service coordinator". Federal and state laws require that families involved in early intervention services have a service coordinator. This person can guide, support, and protect families as they go through the process and can connect families to subsequent services based on the needs of their child.
4. If the child is deemed appropriate for an evaluation, it is at this point when that can occur. The evaluation can then provide more in-depth information on the development of the child and whether or not he/she is eligible for early intervention services. The services are based on whether or not the child presents with a developmental delay in the areas of cognitive, social/emotional, physical, communication, or adaptive functioning. Other children may be eligible if they present with a diagnosis that may result in a significant developmental delay.
5. If the child is determined to be eligible for services, an Individualized Family Service Plan (IFSP) is created. This plan determines, based on the evaluation and the needs identified through that process, what services need to be in place. Services may include assistive technology, audiology services, developmental intervention, health services, nutrition services, occupational therapy, physical



therapy, psychological services, respite care, service coordination, social/emotional intervention, speech-language therapy, transportation, and/or vision services.

6. This step involves putting the IFSP plan into action. Services are monitored on an on-going basis and are adjusted when necessary. The IFSP is formally reviewed every six months, but this can be moved up depending on the changing needs of the child.
7. Finally, the family and the IFSP service providers plan for transition into preschool. Some children will continue to need services while others may be ready to drop services. In any case, steps must be taken to ensure success as the child enters the next developmental stage (Early Intervention Colorado [EIC], 2010).

Additionally, parents must learn about the special education process and how an Individualized Education Plan (IEP) can meet the needs of their child. This involves learning about special education law (IDEA 2004), appropriate accommodations and modified curriculum within the classroom, how to advocate, and what is involved with transitioning from level to level and from school to adulthood.

### **School-age interventions.**

When entering school, parents may want to inquire about what types of interventions are available. When asking such questions, parents must have the knowledge and understanding of appropriate interventions that will work for his/her child. From a school's perspective, research-based interventions are not only ideal, but

are also regulated and backed by the federal government's Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 and No Child Left Behind (NCLB) of 2002. The research-based model began in the medical profession during the 1990s and has since gained acceptance in other professions including education (National Autism Center, 2009). The federal government included it in both NCLB and IDEIA which then mandated educators to provide research-based interventions for students *and* parents. According to Margolin and Buchler, research-based interventions are defined as:

Scientifically based research is defined in the NCLB legislation as "research that involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge relevant to education activities and programs" (NCLB, 2002)...The NCLB legislation, along with guidelines from the U.S. Department of Education, defines scientific research for the goal of determining what works in educational programs and practices. For example, scientific evidence for a literacy program would need to demonstrate convincingly that the program *causes* an improvement in reading. The NCLB legislation describes criteria for research that meets this lofty standard (Margolin & Buchler, 2004).

Research-based practice and implementation requires that professionals use their experience and professional judgment to make decisions, take into account the values of the families they are working with, and implement interventions with fidelity (National Autism Center, 2009). Educating parents of laws, such as NCLB and IDEIA, along with interventions and services that are supported by such laws begins early and continues throughout the life of the child.

ASD is not a childhood disorder as it continues throughout the life of the individual. Many of the interventions currently implemented address the needs of children with ASD but there appears to be limited programming for adolescents and

adults with ASD (Twombly, Holtz & Daub-Sychra, 2011). Parents also face new challenges as their children become older. A study looking at the optimism and parents of children with ASD found that parents are more optimistic in terms of their child's ability to live semi-independently into adulthood, when they are first diagnosed. However, as their child enters adolescence and adulthood, their optimism decreases, causing them to scramble for resources to assist them and their child. The study also found that as children age out of school based programming, the financial burden is then placed on the family limiting access to potential resources (Gray, 2002; Twombly, Holtz & Daub-Sychra, 2011). Again, this is an indication for additional research into programming that addresses the life-long needs of those affected by ASD.

### **The Long-Term Effects of Raising a Child with ASD**

Research supports that parents of children with ASDs report higher levels of family stress and more family problems than families of children with cognitive disabilities such as Down's syndrome (Donovan 1988; Holroyd & McArthur 1976; Lee, Harrington, Louie, & Newschaffer, 2007) or other medical conditions such as cystic fibrosis (Bouma & Schweitzer, 1990; Lee, Harrington, Louie, & Newschaffer, 2007). Parents report increased levels of depression, anxiety, psychosomatic symptoms, limited ability to participate in activities outside the home, marital problems, and health-related issues (Sales 1991; Shu & Lung, 2005). This is due to the behavioral challenges a child with an ASD presents such as self-injury, tantrums, or complex rituals (Lee, Harrington, Louie, & Newschaffer, 2007). Richman and colleagues (2009) found that stress in parents

of children with Cornelia de Lange Syndrome was much higher than in parents of children with Down's syndrome. The noticeable difference between these children and their stress-inducing behaviors were the "severe autistic-like" behaviors of the children with Cornelia de Lange syndrome. This finding supports earlier research that revealed elevated parental stress was related to challenging behaviors, adaptive functioning, and a lack of pro-social behaviors rather than specific to disability (Richman, Belmont, Kim, Slavin, & Hayner, 2009). Many parents of children with autism share similar cognitions such as a decreased locus of control and self-esteem, negative perceptions of their child related to physical characteristics and intelligence, and internal conflict related to their expectations and the realistic expectations of the child in regards to independence (Mori, Ujiie, Smith, & Howlin, 2009).

Another issue that plays a major part in the psychological distress of parents of children with autism is the social isolation parents often feel as a result of limited contact with family and friends. According to Lee et al (2007), families with children ages 3 to 17 with an ASD were 50 to 70 percent less likely to attend religious services and other organized activities outside the home due to negative reactions from other parents (Fox, 2002; Lee, Harrington, Louie, & Newschaffer, 2007). Feelings related to societal rejection are founded in a long history of negative attitudes and responses to parents and their children with disabilities. Originally, the diagnosis of autism was thought to be a result of poor parenting (Kroodsma, 2007; Pisula, 2003). When the disability was first identified in the early 1940's, many professionals felt that the disability resulted from what they called, "refrigerator mothers," which indicated a lack of attachment and lack of

focus on their children (Bettleheim, 1967; National Autism Center, 2009). Although this ideology has since been refuted through extensive research, the belief that the disability is a result of poor parenting still remains (Kroodsma, 2007). In July of 2008, a well-known radio personality made the statement that autism was “a fraud, a racket” and that these children were just “brat[s]” who hadn’t been disciplined appropriately (National Autism Center, 2009). These sentiments may be more prevalent depending on the cultural beliefs. In China, for example, families of children with disabilities often feel shame, and mothers, especially, are publicly blamed for the child’s disability (Holroyd, 2003; McCabe, 2008). The isolation that results from feelings of shame and rejection often decreases one’s peer support group as he/she is less likely to engage with others (Kroodsma, 2007; Rodrique, Morgan & Geffken, 1990). As a result, empowerment (Alat 2006; Dunst & Trivette, 1987; Dunst, Trivette & Cross, 1986) and social support (Alat, 2006; Sarason, Sarason, Shearin, & Pierce, 1987) have become essential foci within parent education programs.

### **Parent Training**

Parent training offers education and support that can address many of the challenges parents face when raising a child with ASD. Below, education and support are broken into two separate parts in order to discuss how each is vital to the training process.

### **Parent education.**

While mental health professionals, teachers, and other experts in such areas as child development are able to address the nuances and complexities of behavior, learning, or functional living skills, a parent is a “specialist” on *his/her* child and the complexities of *his/her* child’s specific and unique behaviors and needs (Briesmeister & Schaefer, p. x, 1998). This is evidence to support why the collaborative relationship between professionals and parents, in the form of parent education, has become an essential piece for successful intervention (Kolb, 2007; Paul & Frea 2002) and why parents remain at the core of the treatment process (Briesmeister & Schaefer, 1998) hence making parent education the most commonly used tool in dealing with behavior issues in children (Carr, 1999; Griffin, Guerin, Sharry, & Drumm, 2010).

Brookman-Frazee (2006) broadly defined parent education as “...programs or trainings designed to provide parents with information or teach them skills” (Brookman-Frazee et al., 2006; Schultz, Schmidt & Stichter, 2011, p. 181). Studies of parent education programs have indicated that they are the most cost-effective way to assist children with ASD and their families (Anderson, Birkin, Seymour, & Moore, 2005; Birkin, Anderson, Seymour & Moore, 2008; Engwall & McPherson, 2003; Frea & Hepburn, 1999; Howlin, 1981). The idea of parent education, which utilizes such constructs as behavioral modification strategies and principles of learning theory (Briesmeister & Schaefer, p.x, 1997), to assist parents of children with disabilities is not a new concept. In the classic case study, *Analysis of a Phobia in a Five-Year-Old Boy*, Freud demonstrates the use of parent education in dealing with a boy named Little Hans

and his phobias and anxieties. Instead of working directly with Little Hans, Freud worked with his father in an effort to address the child's symptoms (Briesmeister & Schaefer, 1998). Training parents as "intervention providers" for children with autism specifically was highlighted by Lovaas's research (1973) when it was determined that children with autism, whose parents were trained on behavior modification techniques, continued to improve behaviorally over time, while children who were institutionalized made no progress or may have even regressed. In 1987, Surgeon General C.E. Koop indicated his thoughts regarding the importance of parent education groups by recommending that professionals and families work together to improve the well-being of children with special health care needs (Brewer, McPherson, Magrab, & Hutchins, 1989). Since then, the use of parent training has been the topic of much research (Alat, 2006; Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993) and has been used extensively to provide parents of children with many disabilities, including ADHD, conduct disorder, and learning disabilities, the tools necessary to become effective in dealing with the unique challenges of raising a child with disabilities.

Although parent education is an effective strategy for addressing the needs of children with a variety of disabilities, it is of particular importance for parents of children with ASDs because of the prevalence and the complexity of the behaviors associated with the disability. Parent education programs have been reported to be effective in providing parents the tools necessary to increase their child's skill acquisition (Hupp & Reitman, 2000; Kolb, 2007; Frea & Hepburn, 1999; Stiebel, 1999) and to decrease disruptive behaviors (Kolb, 2007; Frea & Hepburn, 1999; Vaughn, Wilson, & Dunlap, 2002).

Research indicates that parents of children with autism can be effective in the utilization of behavioral interventions focusing on language and communication skills (Moes & Frea, 2002; Rocha, Schreibman, & Stahmer, 2007; Schreibman & Koegel, 1996). In fact, Moes and Frea (2002) found that interventions involving the family resulted in a greater decrease in behavior problems and a greater increase of on-task behavior as compared to interventions not involving the family (Kolb, 2007). Those interventions completed in the natural environment, such as the home, also proved to be more effective than those completed in clinical settings (Douglas, 1998). Delaney and Kaiser (2001) found that parents of preschool-aged children with autism, through training, were able to successfully manage behavior while also supporting communication needs, which led to an increase in positive interaction (Rocha, Schreibman, & Stahmer, 2007). These positive interactions along with the reduction of negative parent-child interactions are useful in reducing negative behavioral problems (Mcintyre, 2008; Patterson 1982) and in increasing effective parenting practices, while also creating positive parent-child relationships (Eyberg, 1992; McIntyre, 2008; Webster-Stratton & Hammond, 1997; Webster-Stratton, 2001). The optimism parents feel as a result of decreased stress levels can be an important factor in the overall functioning of the family (Gerstein, Crnic, Blacher & Baker, 2009). The ability to implement interventions at home or in the natural environment can result in greater generalization across environments (Rocha, Schreibman, & Stahmer, 2007; Schreibman & Koegel, 1996) and can increase the time the child is in the home rather than being removed because of negative behaviors



necessitating professional assistance, such as a clinical setting (Koegel, Koegel, Harrower, & Carter, 1999; Rocha, Schreibman, & Stahmer, 2007).

Although training programs differ in delivery models, such as home-centered, school-centered, home and school-centered, and distance learning (Cavkaytar, 1999; Yucel & Cavkaytar, 2007), they tend to address similar issues, such as the most appropriate and effective behavior modification methods (Briesmeister & Schaefer, 1998), establishing consistency between home and school, training in respect to the child's disability (Chronis, Chacko, Fabiano, Wymbs & Pelham, 2004), and familiarizing parents with different parenting skills (Cavkaytar, 1999; Yucel & Cavkaytar, 2007). Ideally, trainers will focus on teaching parents research-based procedures that have proven to be effective in clinical, educational, or home settings (Matson, Mahan, Matson, 2009). According to Minjarez et al, (2011) many of the trainings are delivered individually, causing issues with efficiency. Therefore, these authors suggest that additional research is needed to determine the effectiveness of group trainings, which are relatively new for the ASD population (Anan, Warner, McGillivray, Chong & Hines, 2008; Minjarez, Williams, Mercier & Hardan, 2011).

There are a variety of programs addressing the many challenges associated with raising a child with an ASD. However, the "one size fits all" approach may not be as effective as programs that address the specific needs of a particular child and his/her family. Parent education programs that teach specific skills related to a specific need has been correlated with more positive outcomes than programs that impart general

knowledge alone (Kaminski, Valle, Filene & Boyle, 2008; Schultz, Schmidt & Stichter, 2011). An example of a group designed to address the needs of parents with newly diagnosed children is the LAUNCH program developed by The Denver Children's Hospital. LAUNCH is a short-term program offered at The Child Development Unit at The Children's Hospital in Denver. It provides group seminars where parents learn about ASDs and techniques to assist their children with communication, social interaction, and play skills. They also have the opportunity to attend workshops where they learn how to design and implement visual support strategies and how to engage with their children socially, imparting play skills vital to their development. Individual interventions are also available; although, the majority of the program is group focused.

A very commonly taught method is applied behavior analysis (ABA). The Center for Autism and Related Disorders (CARD) defines ABA as:

Behavior Analysis is the scientific study of behavior. Applied Behavior Analysis (ABA) is the application of the principles of learning and motivation from Behavior Analysis, and the procedures and technology derived from those principles, to the solution of problems of social significance. Many decades of research have validated treatments based on ABA (Center for Autism Research).

In a review of published articles, Green, Brennan and Fein (2002) found that the programs that utilized the ABA approach had the following features in common:

1. Treatment was comprehensive and addressed all skill domains while also addressing the specific child's strengths and weaknesses.
2. Various analytical tools, such as differential reinforcement, prompting, discrete-trial instruction, and incidental teaching, were used to "build functional repertoires and reduce interfering behavior".

3. Treatment facilitators were all well educated in the ABA model.
4. “Normal developmental sequences guided selection of treatment goals and short-term objectives”.
5. Parents were trained as “co-therapists”.
6. Treatment was provided through a one-on-one format but slowly progressed to a group format.
7. Training was provided in the child’s natural environment such as home and school.
8. Treatment was provided during 20 to 30 hours per week and also included additional unstructured time for practice.
9. Most programs lasted for 2 or more years.
10. The children involved were typically 3 to 4 years of age.

As previously discussed, parents can gain not only educational information but support for their emotional needs as well. In a study comparing an educational program that also offered emotional support versus strictly an educational program, parents who received emotional support were determined to have better “mastered” the newly acquired skills of the educational program versus parents who received educational information alone.

Throughout any training process, the parent must feel that it is effective. The level of satisfaction that a parent perceives in terms of the effectiveness of an intervention is related to the concept of social validity (National Autism Center, 2009). Social validity is a construct that is evaluated and determined by a teacher or a parent and can greatly

impact the how the intervention is implemented therefore affecting the fidelity of the intervention. For example, if a parent sees the social validity of a particular intervention, then he/she is more likely to carry out the intervention in the home and in the community, increasing the generalizability of the skill. If the parent does not see the social validity, then the intervention will not be carried out as intended, reducing its effectiveness.

Callahan et al., (2008) examined the idea of social validity of a variety of interventions within an educational setting and determined that research-supported interventions were not the highest rated in terms of social validity. Interventions that required more data collection were deemed more socially valid (National Autism Center, 2009); perhaps because many parents felt confident in their data collection abilities, which then produced concrete output. However, regardless of the type of intervention, if parents were trained in a particular research-based intervention, they were more likely to see it as socially valid. This further supports the need for increased educational opportunities for parents. The competency that parents feel as a result of education may also have a positive effect on their psychological wellbeing.

### **Parent support.**

Along with the idea of having a child with a lifelong disability and the isolation one feels as a parent of a child with an ASD, parents also report that failing to receive adequate social support is a significant factor affecting their well-being (Benderix, Nordstrom & Sivberg, 2006; Sharpley, Bitsika & Efremidis, 1997). Parents not only gain valuable skills from educational groups, but they can also obtain emotional support through the engagement with other parents experiencing similar issues to their own (Alat,

2006; Bull, 2003). A study conducted by Tonge et al., (2006) found that a parent education program, for parents of children with ASD, was beneficial to participants' mental health and overall well-being (Tonge, Brereton, Kiomall, Mackinnon, King & Rinehart, 2006). Pisula (2003) found that participation in a parent education group reduced overall stress (Kroodsma, 2007). "Being with other parents who also have children with disabilities, sharing experiences and mentoring each other can help parents cope with their own experiences" (McCabe, 2008, p. 303; Klein & Schive, 2001; Turnbull, Blue-Banning, Turbiville, & Park, 1999). Without information or correct information, parents can experience distress (Kroodsma, 2007). Mothers who were given educational guides and who were supported through the educational process reported higher levels of confidence and lower levels of stress. The benefits of lower stress and higher confidence then led to an increase in positive parenting practices (Connell, Sanders, and Markie-Dadds, 1997; Schultz, Schmidt & Stichter, 2011).

Personal social networks have proven to be effective in overall well-being, especially during stressful times or times of crisis (Alat, 2006; Dunst, Trivette, & Cross, 1986). However, parents may need more than what their personal networks can provide (Kazak & Wilcox, 1984; Kroodsma, 2007). Because these parents are at such high risk for social isolation and for high levels of stress, programs have been designed to increase the social support for this population by way of parent education or training (Boyd 2002; Kroodsma, 2007). Through such programs, parents not only receive valuable parenting skills, but they also receive social/emotional support and have the opportunity to build upon their personal social support networks (Dyson, 1997; Kroodsma, 2007; Peck, 1998).

Even a perceived level of support, which can be created through parent education groups (Boyd, 2002; Kroodsma, 2007) can be effective in increasing the well-being of parents. In a study conducted by Carter, parents involved in a group that allowed time for supporting one another reported lower levels of depression, anxiety, and higher perceived support than parents from a comparison group in which time for support was not given (Kroodsma, 2007).

According to McCubbin and Patterson (1983), the support systems that are available to parents of children with disabilities decrease the demands they feel in the face of the challenges they experience in raising a child with disabilities. Supports can come from a variety of sources. The first source comes from the relationship between the mother and father of the child with the disability (White & Hastings, 2004). A positive marriage has been associated with lower stress levels (Kazak & Marvin, 1984; White & Hastings, 2004). Parents may also receive support from informal sources (Alat, 2006; Valentine, 1993) such as grandparents, aunts and uncles, and those outside the family including religious communities or friends of the family (White & Hastings, 2004). Research has indicated that one of the most powerful informal sources outside the family is other families of children with disabilities. When parents are able to share their experiences with other parents who are dealing with similar challenges, they benefit greatly from a decrease in isolation and stress (Kerr & Macintosh, 2000; Matloff & Zimmerman, 1996; Santelli, Turnbull & Higgins, 1997).

An additional source of support can come from formal relationships such as those with psychologists, doctors, and teachers (Alat, 2006; Valentine, 1993) who are able to

decrease the levels of stress through working formally with the family. However, these individuals have also been reported to increase stress in others depending on the level of perceived social validity and communication (White & Hastings, 2004). Kerr and Macintosh (2000), in studying online statements from parents of children with physical disabilities, found that parents primarily wanted information. They wanted information on the disability, why it occurred, how the disability would affect development, and how professionals could assist them in the future. The Tonge et al study (2006) once again illustrates how important the informational component can be as parents who received information and skill-training alone still benefited in terms of their overall well-being and mental health. However, many parents in the Kerr and Macintosh study felt that the information they received from professionals was “inadequate,” increasing their levels of stress and uncertainty about the future. Once again, this highlights the importance of the collaborative relationship between parents and professionals (Kolb, 2007; Paul & Frea, 2002).

Overall, positive support networks can significantly reduce feelings of social isolation, therefore reducing levels of depression and anxiety. Formal and informal support networks can provide valuable information, offer other assistance such as child care, and also provide social/emotional support (Alat, 2006; Valentine, 1993), in an effort to create positive perceptions of having a child with disabilities (Alat, 2006; Dunst, Trivette & Cross, 1986). Research indicates that parent training programs often provide not only valuable information on how to overcome the challenges associated with a child with ASD but also can provide the emotional support many parents seek. Luther,

Canham, and Young found that parents were most satisfied with education programs when they not only learned about the disability, but were also were allowed to express their feelings and experiences with other parents, which led to better coping mechanisms to deal with the challenges (Linares-Gonzalez, 2006; Luther, Canham, & Young Cureton, 2005). However, if parents do not feel that parent training groups are effective in meeting both their educational or emotional needs, the likelihood of them attending drops significantly (Forehand, Middlebrook, Rogers, & Steffe, 1983; Matson, Mahan, & Matson, 2009).

#### **Factors affecting attendance.**

Parents of children with ASD often find it difficult to participate in parent training groups for a variety of reasons including geographical, financial, and logistical reasons (Kolb, 2007). The logistical issues that arise can make it difficult for some parents to access services. For example, some parents find it difficult to find child care if the children are not involved in the training sessions (Kolb, 2007). Finding child care can be difficult for any parent but, it can be especially difficult for parents of children with disabilities because of the myriad of issues involved such as medical, behavioral, and communicative. Time may be problematic for some as parents may have to take off work or leave their homes for long periods of time (Kolb, 2007). Smith et al., (1994) found that although a factor, transportation is a minor issue in relation to the others. However, Smith speculated that this small group "...may be the most isolated parents and thus be most in need of a PSG (parent support group, p. 135)". Additional factors that impact attendance include work schedules, travel time, and low socioeconomic status (SES;



Chronis, Chacko, Fabiano, Wymbs & Pelham, 2004; Cunningham, Bremner & Secord, 1997). Research shows that parents who fall within higher SES categories are more likely to attend parent education groups (Cleve, 1989; Smith, Gabard, Dale, & Drucker, 1994). It has been hypothesized that parents who fall in the lower SES categories rely more on public resources such as Head Start (Rawlins & Horner, 1988; Smith, Gabard, Dale, & Drucker, 1994) or that they may be too focused on the day-to-day issues related to simply surviving (Gidron, Guterman & Hartman, 1990; Smith, Gabard, Dale, & Drucker, 1994).

Arcia et al. (1993) created a model that looked at mediating factors to participation in parent education groups. The authors propose that there are predisposing family factors such as ethnicity, age of parents, level of education, single mother, and family size that impact participation. They continue by stating that these predisposing family characteristics are also impacted by the family's perception of the problem, which may be impacted by cultural factors, and enabling factors such as time, finances, and program availability (Arcia et al, 1993; Birkin, Anderson, Seymour & Moore, 2008).

While it is difficult for many parents to attend regardless of geographic location, this factor does present especially difficult as, for many, training opportunities simply do not exist. For those living in rural communities, options are limited as resources are allocated based on the number of people living in that area (Symon, 2001). School districts may be reluctant to hire specialists for small populations of students with disabilities (Symon, 2001). Gething (1997) describes these populations of students with disabilities as "double disadvantaged". The quality of medical, educational, and

psychological services is also impacted and often inferior to those offered in more populated areas (Doctoroff, 1995; Kolb, 2007). This quality is often associated with the limited number of specialists in the area. Families living in remote areas, whom require specialized services, face added expenses (Koegel et al., 2002; Kolb, 2007). As a result, many of these families may opt not to access specialized programs, impacting the services they and their children receive. However, there may be times when parents do not have an option. For example, a 2001 survey in China revealed that 50% of children with disabilities did not receive any type of services. In 73% of those receiving services, interventions were provided by parents. As a result, the parents reported being negatively impacted, both in their personal lives and in their careers, due to the lack of training and support (Wang, 2008). Additionally, many parents had to leave their work place for extended periods of time to care for their children (Lin et al., 2000; Wang, 2008).

In Poland, families of children with ASD are confronted with similar issues and can be considered “double disadvantaged”. According to Dabrowska and Pisula (2010), it is difficult to find professionals who specialize in children with ASD. According to these authors, “...only a small proportion of children and parents receive appropriate support” (p. 267). This is due to financial factors as well as issues related to the scarcity of professionals in the smaller towns and villages (Dabrowska & Pisula, 2010; Rajner & Wroniszewski, 2001). Parents are then left to their own devices to deal with the complexities of ASD and often form their own support organizations without the support of specialized professionals (Dabrowska & Pisula, 2010) limiting their access to research-based interventions.

The two cases above underscore the need for research into efficient and cost-effective programs that provide access to research-based interventions to those in areas with little to no resources. In these situations, distance learning options have been created and are considered to be viable alternatives (Yucel & Cavkaytar, 2007).

### **Distance Education**

Because of the inequities in accessing counseling/educational services due to geographical, financial, and logistical reasons, professionals have attempted to overcome these challenges by utilizing technology to reach distant populations (Simpson, 2009). For more than a century (Kiryakova, 2009), educators, psychologists, and other professionals have implemented various forms of distance learning programs using such technologies as letter writing (Davidson & Birmingham, 2001; Simpson, 2009), telephone (Lester, 1995; Simpson, 2009), email (Robinson & Serfaty, 2001; Simpson, 2009), radio, television, audio and video conferencing (Chute, Thompson, & Hancock, p. 24, 1999). Although useful, each of these modes is ultimately measured against the “gold standard” (Ritterband, Gonder-Frederick, Cox, Clifton, West & Borowitz, 2003) of face-to-face communication. Much research has been conducted exploring the effectiveness of distance learning versus face-to-face learning concluding with mixed results. Some analyses indicate that human contact is not necessary in the learning environment (Huerta-Wong & Schoech, 2010; Witt, Wheelless, & Allen, 2004), while other analyses indicate that learners are more satisfied when the environment provides social contact (Allen, Bourhis, Burrell, & Mabry, 2002; Huerta-Wong & Schoech, 2010). For example, a meta-analysis, conducted by Allen et al. (2002) concluded that technology used as a

means to deliver educational content did not appear to affect student outcomes and level of satisfaction. On the contrary, Richardson (2003) determined that high perceptions of social presence resulted in higher perceptions of learning and overall satisfaction. Factors that led to inconsistent findings are learning styles and comfort with technology (Allen, Bourhis, Burrell, & Mabry, 2002). However, with increasing use of technology and advances in equipment, social contact can be provided while still learning from a distance.

### **History of distance education.**

In her review of distance education, Kiryakova (2009) defines distance learning as “...a form of education in which the participants [teachers and learners] are physically separated and communicate by different means and at different times” (p. 29).

According to Kiryakova, distance education in its purest form started in the 19<sup>th</sup> century when teachers sent materials such as lectures, instructions, and assignments, via mail, to students who would complete the assignments and send them back to the teacher. In 1873, Anna Ticknor created opportunities for American women to learn out of their homes. From her definition, Kiryakova differentiates the main characteristics of distance education as the following:

1. Separation of teacher and learners in space and time;
2. Use of different media to realize the interaction among teacher, learners and educational content;
3. Provision of two-way communication between teacher and learners;
4. Control of the learning process by the learners rather than the teacher.

She then describes the elements that separate distance education from traditional methods. These elements include the following:

1. Sociability – distance education satisfies the continuously changing needs of society;
2. Flexibility and independence – distance learning gives an opportunity to learn independent from time and place;
3. Individuality – the instructor personalizes the content and technology utilized based on the learners' needs.

As technology increases and the needs of society change, the options and responsibilities of the professionals offering distance education programs change and become more difficult (Chute, Thompson, & Hancock, 1999). With technology, distance education can take on different meanings depending on the goal of the teacher and/or learners.

#### **The internet and its application to distance learning.**

Over time, distance education has changed, primarily due to rapid changes in technology, allowing distance learning to rely less on “correspondence” and to be more like traditional learning environments (Adrian, 2002). In recent years, professionals have utilized various technologies to provide education from a distance such as audiotapes, videotapes, interactive CDs, and the Internet (Vismara, Young, Stahmer, McMahon-Griffith & Rogers, 2009) to provide learning opportunities. The Internet has also broadened the term distance education by providing a range of services to those who are in search of information or support. The Internet can reach people regardless of their geographical location in relation to the service provider (Ritterband, Gonder-Frederick,

Cox, Clifton, West & Borowitz, 2003); therefore, this technology has proven to be useful in providing social support for parents of children with disabilities (Baum, 2004; Bragadottir, 2008; Huws, Jones, & Ingledew, 2001), college students dealing with psychological problems (Freeman, Barker, & Pistrang, 2008), and individuals dealing with cancer (Beaudoin, & Tao, 2007) and HIV/AIDS (Mo, & Coulsin, 2008). Through this medium, professionals have expanded their services by providing information and support through Web-based options to those who previously received inadequate services or those who did not receive any type of services because of their location and/or situation (Johnstone & Jones, 1997; Keller, 1997; Rayburn, & Ramaprasad, 2000; Vines, Thorpe, & Threlkeld, 1997). The term “web-based instruction” has been used to describe a variety of Internet uses aimed at providing information to a specific group with a specific need. This includes websites that are simply “deliverers” of information. These sites do not aim to be “educators” but instead provide information to anyone who wants it, such as those that provide forums for blogging, entertainment, and news-related articles. In other words, learning is not the goal. However, educational websites do aim to educate, much like public television or radio programming may aim to educate its viewers/listeners but without the means or the need to assess what is being learned. There are formal instructional sites that do aim to educate and assess the learning of its users, which are considered “on-line courses” (Berry, 2002). With its ability to overcome social and geographical barriers, the Internet aims to reach anyone with access.

Traditionally, higher SES individuals have been the primary users of the Internet for informational purposes. While this continues to be the case, according to the US Department of Commerce (2002), those within the lowest SES group, earning less than \$15,000 per year, showed the largest increase in users of the Internet. Also according to this report, use of the Internet by African-American and Hispanics increased more than in any other racial or ethnic group (Scharer, 2005). A study conducted by Dunham et al., determined that young single mothers who were more isolated used the Internet for support and information more than mothers who were less isolated, providing services to those who previously were underserved (Scharer, 2005). Because more individuals across all income levels are accessing the Internet, including those within the lowest SES, health providers are able to provide services to a broader, and perhaps needier, population (Scharer, 2005; US Department of Commerce, 2002).

The Internet has been useful in not only educating its users, but also linking them to much needed resources such as health providers (Scharer, 2005). The Internet can be particularly helpful for rural populations in providing health-related services. These individuals, who may otherwise lack services due to issues with traveling long distances, can now access and obtain health-related information via their computer (Scharer, 2005; McNamara, 1994). According to the US Department of Commerce (2002), rural households are the fastest growing in terms of Internet use perhaps for this reason (Scharer, 2005). As of 2000, there were over 100,000 health-related sites providing users with information regarding a variety of diagnoses and disorders (Kolata, 2000; Ritterband, Gonder-Frederick, Cox, Clifton, West & Borowitz, 2003). Research of these

sites has produced primarily positive results indicating that Internet interventions can be feasible and effective. They also show that psychological services can be feasibly attained via the Internet, allowing for individuals, who would not normally seek help, to access support without leaving their homes (Ritterband, Gonder-Frederick, Cox, Clifton, West & Borowitz, 2003).

In addition to providing users with information, both formally and informally, and linking them with health organizations, users have also accessed the web for social support through online support groups. Online support groups or communities refer to a group of people, connected via the Internet, who communicate regarding common issues (Preece, 2000; Shen, & Khalifa, 2008) either in real time, known as synchronous communication, or time delay, asynchronous communication (Huws, Jones & Ingledew, 2001). Academia utilizes online discussion groups, or listservs, as a “pedagogical tool” to reach specific groups of students learning specific content (McFann, 2004). A research study of the Internet in 1997 concluded that there were thousands of specialty sites and hundreds of online groups with the sole purpose of discussing issues pertinent to their members’ needs while also providing social support (Jones, & Lewis, 2001; Mickelson, 1997). The numbers of these sites and groups have grown rapidly over the last 13 years because of their popularity as well as the increase in numbers of people accessing the Internet each year to obtain information regarding health-related advice, information, and support.



### **Social support via the internet.**

The literature differentiates between five potential forms of social support (Mo, & Coulson, 2008). These include informational, emotional, tangible, esteem, and social network support (Cutrona, & Suhr, 1992; Mo, & Coulson, 2008; Wills, & Fegan, 2001). According to a study completed by Mo and Coulson (2008) regarding the online social support of persons with HIV/AIDS, computer-mediated support groups can provide all of these types of support. Similar findings were reported in a study researching the role of online support groups for individuals with food allergies (Coulson, & Knibb, 2007). All of the participants reported joining the online group as a result of the accessibility, the social support, and the dissemination of coping strategies. Researchers who studied the online experiences of couples coping with infertility (Malik, & Coulson, 2008) found that participants reported a reduction in social isolation and an increase in empowerment through the online community.

Instead of simply accessing a website, users are benefitting from email discussion groups for the purpose of obtaining psychological and social support (Braithwaite, Waldron, & Finn, 1999; Finn, 1999; Huws, Jones & Ingledew, 2001; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). For example, in a study of email messages posted by individuals with physical disabilities within an online support group, Braithwaite et al (1999) found that emotional and informational support messages were offered more than any other type of message. The researchers indicated that these types of supports are often found in the traditional learning environment and also provided evidence of valuable support among computer-mediated support groups (Huws, Jones &

Ingledew, 2001). Although many of the participants in online groups are essentially strangers, there is a sense of community as if they have met (Scharer, 2005). Huws et al., (2005) points to the research conducted by Jones and Lewis (2001), which studied a support group consisting of parents of children with Down Syndrome. This exploratory study found many celebratory posts conveying a message of hope. These messages also provided support and validation among its users; much like a non-mediated community would provide (Huws, Jones & Ingledew, 2001). Through all of its benefits, the Internet is considered a “first-rate” source (Fleischmann, 2005; Fleitas, 1998) for children and their families who cope with health-related issues on an ongoing basis, including families of children with autism (Huws, Jones & Ingledew, 2001).

#### **Parents of children with autism and the internet.**

Since the Internet has proven useful in providing information and support in the areas of education, psychology, and health, it seems natural for parents of children with autism to access and utilize the technology. Although the study of parents of children with autism and their use of the Internet is still relatively new, there is evidence that parents have begun to use it to discuss their challenges and to connect with other parents, through listservs, dealing with similar issues, therefore creating virtual support environments (Fleischmann, 2005; Huws, Jones & Ingledew, 2001). An example of such evidence is contained within Huws et al study (2001), which looked at a variety of messages posted by parents of children with autism. These researchers found that although the email group provided social support, it also provided parents the opportunity to listen to others who share their quest for information in order to make

sense of the diagnosis. Parents were also allowed to further explore their thoughts and ideas through objective and constructive feedback (Huws, Jones & Ingledew, 2001). The VerbalBehavior group through YahooGroups is another example of a similar site used in the aforementioned study. The VerbalBehavior group allows parents to ask questions regarding treatments, symptoms, or other issues and to receive guidance from professionals and other parents. The feedback is often immediate and based on research. Overall, the research to date is limited with this particular population, which creates the opportunity for researchers to further investigate how service providers can better utilize technology to train and support parents of children with autism.

### **Considerations for Using Technology to Educate Parents**

Although much of the research regarding online education and support groups has resulted in positive outcomes, there are some issues that need to be considered prior to implementing such a group. In some studies, researchers have found that computer-mediated learning environments have higher than average attrition rates (Frydenberg, 2007; King, 2002; Liu, Gomez, Khan, & Yen, 2007; Moshinskie, 2001; Phipps & Merisotis, 1999; Slager van Tryon, & Bishop, 2009). Users of online courses in particular report feeling socially disconnected, missing the traditional interaction with teachers and peers with its usual social cues they experience during face-to-face sessions (Haefner, 2000; Menchaca & Bekele, 2008; Reisetter & Boris, 2004; Slagter van Tryon, & Bishop, 2009). Coulson and Knibb (2007) found that participants of an online support group had difficulty trusting information posted by its members as a result of the missing social cues. Other complaints have included rare cases of negative messages being

posted, breaches in confidentiality (Kane & Sands, 1998; Robinson, Patrick, Eng & Gustafson, 1998; Sands, 1999; Scharer, 2005), and misunderstandings of the true meaning of what someone is attempting to convey via email (Scharer, 2005). The social aspects of the negative responses to online groups are partly related to the concept of social presence.

### **Social presence.**

The construct of social presence was first identified by Short, Williams, and Christie (1976) (Shen, & Khalifa, 2008) and has undergone several shifts in its meaning due to changes in the way humans communicate. Biocca et al. (2001) defines social presence as the following:

The moment-by-moment awareness of the co-presence of another sentient being accompanied by a sense of engagement with the other....as a global, moment-by-moment sense of the other, social presence is an outcome of cognitive stimulations of the other's cognitive, emotional and behavior dispositions (Shen, & Khalifa, 2008, p.727).

Shen and Khalifa (2008) build on this definition and define social presence as the awareness of others by "...cognitive and affective engagement in computer-mediated social spaces". This form of presence then is not confined to face-to-face meetings (LaMendola, 2010) but can be encountered in mediated environments. Garrison and Anderson (2003) describe the essential elements to providing social presence in mediated environments as affective, open communication, and cohesive responses (LaMendola, 2010). Research indicates that a mismatch between the medium of information delivery and the particular social need of the group can negatively impact the level of social presence (Chou, & Min, 2009; Weinel, Bannert, Zumbach, Hoppe & Malzahn, 2011).

The level of social presence has been linked to the level of satisfaction one feels in an online setting (Weinel, Bannert, Zumbach, Hoppe & Malzahn, 2011).

### **Telepresence.**

In an effort to go beyond social presence, making the interaction between humans and technology seamless, and allowing the user to concentrate on the content and not the technology, is at the root of the concept of telepresence. The spatial and social cues involved in telepresence allow for the “illusion of nonmediation” (Horvath, & Lombard). In other words, humans can interact from a distance using technology that gives the users the sense that they are in the same room at the same time (Walker, & Shepard, 1999). Telepresence technology is enhanced videoconference technology (Engebretson, 2010) that can allow others to meet face-to-face without being in the same room. Due to decreasing costs and an increase in the mobility of technology, the authors of Telepresence posit that there will be an “explosion” in the use of the technology. However, currently, the price for systems is fairly high, ranging from \$125,000 to \$350,000, causing organizations to find compelling reasons to justify their installation such as saving on travel expenses and extending their customer/client base (Engebretson, 2010).

Until telepresence systems become more accessible, less expensive tools can be used. For example, anyone with an Internet connection and a computer camera can access web-based sites that provide audio and visual information, increasing the social presence, and effectiveness for web-based meetings and groups.

Once example of web-based site is BigMarker.com. BigMarker.com is a video-conferencing website that allows for such features as the ability to record conferences for later playback, the use of Word documents and PowerPoints, and a shared desktop. These features allow for more interaction and flexibility of presentations. Additionally, the ability to play back conferences at a later time will allow participants the opportunity to view portions they may have missed or to review material increasing the likelihood for retention of information. While this site is free for small groups, there is a small monthly fee for groups larger than 5 and up to 100.

## **Conclusion**

This literature review contained information about children with autism and the stress their parents encounter due to the unique behaviors that accompany ASD. While parent training is an effective intervention for both the child and his/her parent, accessibility to such services do not exist for some. Distance education has been found to be affective in providing education. However, the question remains as to whether distance education in the form of web-based technology, can be effective in providing education *and* social/emotional support to parents of children with ASD.

## **Chapter 3: Methods**

### **Introduction**

Research regarding services, and service delivery models, for parents of adolescents with autism, is limited. Much of the research conducted thus far has focused on young children and their parents. However, with 1 in 88 children diagnosed with autism (<http://www.cdc.gov/Features/CountingAutism/>), the need for research and related services for the adolescent population will become increasingly more important as these children, and their parents, enter this stage in life.

### **Research Questions**

This study attempted to investigate the use of technology as a viable option for providing educational and emotional support to parents of adolescents with ASDs. The results of this study answered the following research questions:

1. What is the effect, based on quantitative measures, of web-based groups on their ability to
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?

- b. Decrease stress by providing social and emotional support to parents of adolescents with autism or a related disorder, as measured by a pre and post stress inventory?
- 2. What is the effect, based on qualitative information, of web-based groups on their ability to
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?
  - b. Decrease stress by providing social and emotional support, to parents of adolescents with autism or a related disorder?

As this is a pilot study the goal was to explore the effects of this content delivery method and as a result a comparison group was not used providing greater understanding of the efficacy of the web-based intervention. However information gathered regarding this approach was compared to the information available within the literature regarding traditional delivery systems.

The purpose of this chapter is to present the procedures that were followed in order to answer the two research questions. It is important to provide the following information in order for other researchers to adequately judge and/or replicate this study (Roberts, 2010). Items to be discussed include the research design, population and sampling procedures, group facilitation, instrumentation, data analysis, and limitations.



## Research Design

This research study employed a mixed methods design that utilized a concurrent triangulation approach. Figure 1 illustrates this design. According to Creswell (2009), when utilizing a mixed methods design “...the researcher collects both quantitative and qualitative data concurrently and then compares the two databases to determine if there is convergence, differences, or some combination” (Creswell, 2009, p. 213). This process is useful in offsetting the weaknesses found in each of the methods by using separate quantitative and qualitative methods. The data from these two methods are then merged and interpreted concurrently. As with many mixed methods studies, this study first provided quantitative results followed up with qualitative information to support or discount the quantitative results.

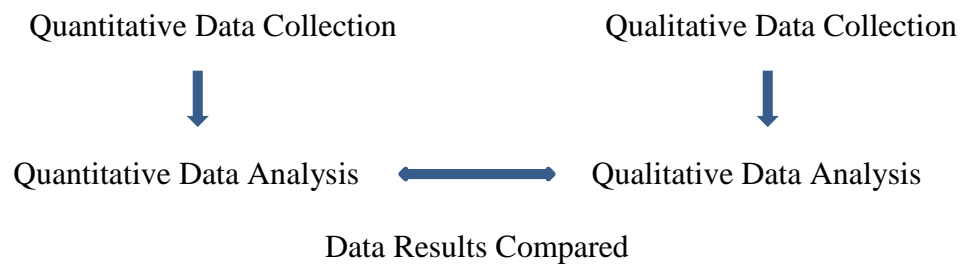


Figure 1. Flow of a concurrent triangulation approach. Adapted from Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. (3 ed.) p 213. Thousand Oaks, CA: Sage.

Quantitative tools were used to measure any change in stress levels and knowledge acquisition that occurred throughout the treatment. This procedure of using qualitative and quantitative measures provided evidence of the validity of the treatment. A pretest was used to obtain a baseline measure of the parents' stress levels and knowledge regarding the group session topics. A test was given post treatment to measure stress levels and knowledge acquisition after the groups had ended. The data gathered from these tools were then analyzed using a *t* test for paired samples, which will be discussed later in this chapter.

During the qualitative phase, the researcher utilized a questionnaire to obtain anecdotal information regarding participants' experiences with and preferences towards parent groups; their feelings of depression, isolation, stress related to parenting a child with ASD; their confidence regarding the topics of stress reduction, IEP's, puberty, and the transition to adulthood; and their experiences within the group setting of the sessions. This qualitative information was used to look for themes and to begin to understand how parents of adolescents with ASD may benefit from groups provided using Internet technology. Additionally, this information provided important insight into the personal experiences of the participants that could not be gathered through quantitative measures. The personal reflective information elicited attitudes, feelings, specific likes and dislikes, and personal values that were unique for everyone.

## **Recruitment**

The initial population of interest comprised of parents living in communities where there is limited access to services and supports to address the challenges of raising a teen-ager with an ASD. However, due to the nature of this pilot study, interested participants were invited regardless of their geographic location.

Initial recruitment efforts involved notifying school districts, area Boards of Cooperative Educational Services (BOCES), hospitals, and the Autism Society of Colorado with the information regarding the study so they could then disseminate the information to potential participants. For every district contacted, individual IRB applications were submitted. However, none of the applications were approved, therefore restricting the researcher from progressing further. This proved to be a difficult challenge in the recruitment efforts. Although the parents of children with ASD were the target population, school districts felt as though this population of children was “over-researched” therefore the study was not approved. As a result, other agencies were notified such as the ARC of Colorado, Developmental Pathways, the University of Northern Colorado, and The Joshua School. This contact included direct communication which resulted in more success and acceptance of the study. The researcher relied on word of mouth from service providers working within the autism community to communicate with potential participants. This also proved to be more successful than recruitment efforts with individual school districts.

## **Population and Sampling Procedures**

Initially 21 parents contacted the researcher for additional information. Twelve parents consented to participate and 8 (67%) ultimately completed all 4 group sessions. Of the 4 (33%) who initially gave their consent to participant but did not complete the study, 3 never started the study and did not provide any information as to why. One participant started the first session but withdrew immediately after it began. When contacted after the session, the participant stated that it would not fit into her busy life.

Of the 8 participants who completed the study, all 8 (100%) were female with an average age of 43.75 years old. Seven (87.5%) of the 8 reported being the biological mothers of adolescents with an ASD and 1 identified herself as the maternal aunt who had guardianship of her adolescent nephew. The average age of the adolescents with an ASD was 16.13 years of age. Two (25%) of the participants indicated that they were widowed and 6 (75%) indicated that they were married. All 8 (100%) participants reported having at least 2 years of college education and 6 (75%) indicated that they work outside of the home.

## **Procedures**

### **Group facilitation.**

The sessions were facilitated using BigMarker.com. BigMarker is a video-conferencing website that allows for such features as the ability to record conferences for later playback, the use of Word documents and PowerPoints, and a shared desktop. These features allow for more interaction and flexibility of presentations. Additionally, the ability to play back conferences at a later time will allow participants the opportunity

to view portions they may have missed or to review material increasing the likelihood for retention of information. Anyone with an Internet connection and a webcam has access to BigMarker.com.

The facilitator of the group sessions was a graduate student with experience and an interest in this type of work and in this population. She was compensated for her time and reimbursed for any travel expenses. The facilitator remotely facilitated the group session from the University of Denver. Training was provided to the facilitator with regard to the curriculum as well as the technology prior to the first session.

Sessions lasted no more than 1 and ½ hours each. Each participant received a brief online training session attempting to eliminate user error and technological issues during sessions. Prior to the start of the sessions, participants completed an online pre-questionnaire regarding their experiences parenting a child with ASD and with previous parent support groups. They also completed an online copy of the Stress Index for Parents of Adolescents (SIPA) prior to the start of the group sessions. These two measures were completed in an effort to assess the knowledge and stress levels of each participant. After four sessions, the group concluded and participants again completed an online questionnaire, gathering information on participants' personal impressions of the group sessions. A post-test and SIPA were also completed to determine if the group session had any impact on their knowledge and/or social/emotional functioning. Before each session, participants completed a pre-test regarding the specific topic to be discussed. A post-test immediately after each session was completed to explore knowledge acquisition.

In an effort to maintain consistency between videoconference group sessions, a check on comparability of instruction was added. Each session was monitored, recorded, and reviewed with the instructor to check for inconsistencies. These inconsistencies were to be reported as potential limitations. Consistency was also gained through a strict and thorough curriculum that guided the facilitator step-by-step.

### **Instrumentation.**

Although the essence of this study focused on the delivery model, the content and the support given to the participants through the process are equally important. Because research for this particular population is limited, the production of “curriculum” for groups such as this are also limited. As a result, an existing curriculum was not used for this study. Instead, the content was developed specifically for this study. In order to provide relevant information to the participants, the researcher completed an extensive literature review, informally surveyed parents of children and adolescents with autism whom he worked with, and used his 10 years of experience as a school psychologist to develop themes that guided content development. The themes that surfaced are listed below with a brief explanation.

- Middle and High School Educational Issues – Transitions are particularly difficult for children with ASD. Middle and high school transitions present with new challenges, different settings, new people and novel situations that require careful planning and consideration. Some of the considerations and structures that need to be in place at the time of transitions include the IEP and associated services, classes, therapies, and behavior management strategies.

- Puberty – Research indicates that puberty is a difficult time for all adolescents but especially difficult for those on the autism spectrum. Parents need to know what to expect and how to deal with difficult behaviors and issues such as sex and dating.
- Transition to Adulthood – Often parents are left wondering what their child will do after they age out of the public school system and can be overwhelmed with navigating the system. This topic would include employment, guardianship, SSI, therapies, group homes, and other resources to assist with these issues.
- Self-Care for Parents – The extensive literature review indicated that parents of children with autism are at higher risk for such issues as increased stress, depression, anxiety and social isolation. Parents often need support and guidance in developing the tools necessary to keep themselves healthy. This is vital as healthy parents are often more capable of utilizing positive parenting skills when dealing with their child, which is especially important for parents of children with spectrum disorders.

Once this curriculum was developed, the researcher asked parents not participating in the study, and other professionals in the field to review the content for consistency, applicability, and practicality. This was an important step in the study as the researcher wanted to have content that was supported as valid by experts.

One of the research questions asked if a group facilitated using technology can be effective in providing information. The pre- and post-tests and questionnaires, based on the content of the curriculum and the participants' experiences, were used to answer this

question. These measures were provided online and included 10 multiple choice questions that provided the researcher with valuable data regarding what parents knew prior to the group sessions and what they took away from the session. These data were then compared to the information gathered from the qualitative measures to look for inconsistencies.

The second question answered by this study was whether or not a group facilitated using technology can be as effective in providing social/emotional support as a face-to-face group. To measure this variable, the researcher chose to use the Stress Index for Parents of Adolescents (SIPA). This test expands on the original Parenting Stress Index (PSI) to include parents of children ages 11 to 19 and is useful in measuring stress and other negative factors associated with parent and adolescent interaction. The SIPA consists of 90 questions using a 5-point Likert scale ranging from “strongly agree” to “strongly disagree”. The questions are then used to form four subscales designed to measure the adolescent characteristics based on parent perception. These four areas are moodiness/emotional lability, social isolation/withdrawal, delinquency/antisocial, and failure to achieve or persevere. Additionally, there are four subscales that measure parent characteristics such as life restrictions, relationship with spouse/partner, social alienation, and incompetence/guilt. All eight subscales are then used to identify specific areas of stress in the parent-adolescent relationship leading to possible therapeutic recommendations. According to the manual, the SIPA is “highly reliable” with internal consistency for the eight subscales exceeding .80. “The alpha coefficients for the three domains (adolescent, parent, adolescent-parent relationship, and the Index of Total



Parenting Stress exceed .90”

(<http://www4.parinc.com/Products/Product.aspx?Productid=SIPA>). A four-week test-retest of reliability resulted in adequate reliability coefficients (.74 to .91) suggesting consistency over time. Similar studies have used the SIPA to determine parents’ levels of stress before or after an informational group. One such study is “An Educational Workshop for Parents of Children with Asperger’s Syndrome” which used the SIPA in a test-retest format prior to and post intervention (Kroodsma, 2007). Although the results were not significant, the tool was useful in gaining pre and post intervention levels of stress in the participants

Similar to the aforementioned study, participants’ stress levels in this study were measured before and after the group sessions. An increase in scores, meaning lower stress levels among parents, in either the control or experimental group, would indicate that the particular model they were exposed to was beneficial.

The final instruments used in this study were two questionnaires consisting of several open-ended questions regarding participants’ personal impressions and experiences prior to and while participating in the study. These were useful in tapping into the unique perspectives of each participant to find out what their previous experiences have been with parent groups, their attitudes going into the study, and what worked or what didn’t work after the study had concluded. Because each child on the spectrum is unique, the experiences of the parents of these children are just as unique. Therefore, this data was crucial to fully understanding the effectiveness and in guiding future studies aimed at

measuring the effectiveness of videoconference groups for parents of children with disabilities.

### **Data analysis.**

The quantitative data were analyzed using the  $t$  test for paired samples. Because this study was considered a single-factor repeated measures study, or a within-subjects study, this analytical tool was useful in determining any significant difference, or change, between the repeated measures or levels (pre and posttests) with regard to stress reduction and knowledge acquisition.

Once the qualitative data were gathered, they were interpreted based on themes that emerged. To assist with this process, the software program, ATLAS/ti, was utilized. The qualitative data was coded, categorized and classified to observe emerging themes. The quantitative data were then embedded into the process and cross-referenced with the qualitative data to look for consistencies or inconsistencies and to support possible theories. Some of the qualitative information was also used in isolation giving firsthand accounts of what it was like to participate in the group sessions.

## **Chapter 4: Results**

### **Introduction**

This study utilized a mixed methods approach to explore the effectiveness of a web-based group for parents of adolescents with an ASD in providing education and social support. The quantitative tools along with the qualitative information provide insight into changes that occurred in participants' stress and knowledge acquisition. The results are presented in three sections: (1) participants and participant attrition; (2) quantitative findings; (3) qualitative findings.

The first section describes the participants who completed the study as well as a brief discussion on participant attrition. The second section reports the results and analysis of the data obtained from the quantitative measures. The analysis includes information garnered from paired samples t tests that were conducted using the pre and posttest data measuring changes in stress and knowledge acquisition. Due to the exploratory nature of this study, as well as the small sample size, the significance level of the paired sample t test was set at  $\alpha < .05$ , so as not to overlook any patterns that may have occurred.

The third section explores the findings from the qualitative phase. The qualitative phase utilized pre and post treatment questionnaires in an effort to obtain anecdotal information regarding participants' experiences with and preferences towards parent groups; their feelings of depression, isolation, stress related to parenting a child with ASD; their confidence regarding the topics of stress reduction, IEP's, puberty, and the

transition to adulthood; and their experiences within the group setting of the sessions.

The information provided through these questionnaires was analyzed using a grounded theory approach (Cresswell, 2007; Strauss & Corbin, 1998) to guide the exploration of themes that developed. Software (ATLAS.ti7) was used to code and categorize information that then was used in theme generation.

### **Participants**

Out of the initial 12 parents who consented to participation in this study, 8 (67%) ultimately completed all 4 group sessions. Of the 4 (33%) who initially gave their consent to participate but did not complete the study, 3 never started the study and did not provide any information as to why. One participant started the first session but withdrew immediately after it began. When contacted after the session, the participant stated that it would not fit into her busy life.

Of the 8 participants who completed the study, all 8 (100%) were female with an average age of 43.75 years old. . Two (25%) of the participants indicated that they were widowed and 6 (75%) indicated that they were married. All 8 (100%) participants reported having at least 2 years of college education and 6 (75%) indicated that they work outside of the home. Seven (87.5%) of the 8 reported being the biological mothers of adolescents with an ASD and 1 identified herself as the maternal aunt who had guardianship of her adolescent nephew. One parent reported having three children identified with an ASD, and one parent reported having two. The other parents reported having only one child with the diagnosis. Among the children who had received the diagnosis, 2 were female (18.2%) and 9 were male (81.8%). The average age of the

adolescents identified with an ASD was 15.72 years of age. See Table 3 for additional demographic information.

Table 3

*Demographic Characteristics of Participants (N = 8)*

Characteristics	n	%
<i>Relationship to Adolescent with ASD</i>		
Biological Mother	7	87.5
Maternal Aunt	1	12.5
<i>Marital Status</i>		
Married	6	75.0
Widowed	2	25.0
<i>Education</i>		
Some College	2	25.0
4 year College	3	37.5
Graduate School	3	37.5
<i>Adolescents' ASD Diagnosis</i>		
Asperger's	2	25.0
Autism	3	37.5
PDD – NOS	2	25.0
High Functioning Autism	1	12.5
<i>Number of Children in Home with an ASD</i>		
3	1	12.5
2	1	12.5
1	6	75.0
<i>Age of Children in Home with an ASD</i>		
13	1	9.1
14	2	18.2
15	2	18.2
16	3	27.2
17	1	9.1
18	2	18.2

*Table 3 Continued*

*Gender of Children in Home with an ASD*

Male	9	81.8
Female	2	18.2

---

**Quantitative Findings**

The objective of this section is to consider the quantitative data analysis to answer the first research question of whether or not the web-based group was effective in decreasing the participants' stress levels and increasing their knowledge base regarding IEP's, puberty, and the transition to adulthood.

**Parent stress.**

Participants completed the Stress Index for Parents of Adolescents (SIPA) before and after the four sessions to measure any change in stress levels. The SIPA asks respondents to rate problematic behaviors of their adolescent, and to rate areas of their lives affected by parenting an adolescent, such as relationships and social alienation, leading to an increase in overall stress. High scores indicate high levels of dysfunction/stress. The mean pretreatment total score was 218.75 which is in the 74<sup>th</sup> percentile and is classified as within normal limits. The posttreatment total score of 211.25 is in the 70<sup>th</sup> percentile and is also classified as within normal limits. This mean decrease of 7.5 points was not statistically significant,  $t(7) = .223, p \geq .05$ . Additionally, the effect size estimate ( $d$ ) based on the pretreatment standard deviation was .24, indicates a small effect size. Table 4 contains the results of analysis for each of the domains, in bold, of the SIPA and the subscales that make up each domain

Table 4

*Pre and Post SIPA Results*

Domain	M <sub>pre</sub>	SD <sub>pre</sub>	M <sub>post</sub>	SD <sub>post</sub>	<i>t</i>	<i>p</i>	<i>d</i>
<b>Adolescent Domain</b>	<b>111.25</b>	<b>14.12</b>	<b>107.00</b>	<b>16.97</b>	<b>1.46</b>	<b>.19</b>	<b>.30</b>
Moodiness	34.00	7.37	33.38	8.98	.62	.56	.08
Social Isolation/ Withdrawal	29.62	4.18	27.75	3.06	1.83	.11	.40
Delinquency/ Anti-Social	18.75	6.27	18.62	6.07	.19	.86	.02
Failure to Achieve Or Persevere	28.62	6.50	27.25	5.26	.77	.47	.21
<b>Parent Domain</b>	<b>75.88</b>	<b>18.56</b>	<b>73.25</b>	<b>20.18</b>	<b>1.04</b>	<b>.34</b>	<b>.14</b>
Life Restrictions	19.12	7.28	21.12	6.75	.47	.66	.27
Relationship w/ Spouse/Partner	15.12	7.86	13.75	8.16	1.77	.12	.17
Social Alienation	15.88	5.72	15.38	5.66	.61	.56	.09
Incompetence/Guilt	22.38	5.71	23.00	6.10	.57	.59	.11
<b>Adolescent-Parent Relationship Domain</b>	<b>75.88</b>	<b>18.56</b>	<b>73.25</b>	<b>20.18</b>	<b>.63</b>	<b>.55</b>	<b>.16</b>
<b>Index of Total Parenting Stress</b>	<b>218.75</b>	<b>31.42</b>	<b>211.25</b>	<b>37.23</b>	<b>1.34</b>	<b>.22</b>	<b>.24</b>
<b>Life Stressors</b>	<b>3.50</b>	<b>2.45</b>	<b>3.38</b>	<b>2.20</b>	<b>.55</b>	<b>.60</b>	<b>.05</b>

### **Knowledge acquisition.**

The second variable that this study explored was knowledge acquisition. Four group sessions were conducted on topics that parents of adolescents need as their child transitions from one developmental stage to the next. The first session focused on stress reduction for the parents, which was discussed previously. The following sessions discussed the topics of IEP development at the secondary level, puberty and related issues, and finally the transition to adulthood. Prior to each session, the participants completed a pretest covering the upcoming topic. After each session, participants were then asked to complete a posttest to assess their knowledge acquisition.

Beginning with the IEP session, the mean pretreatment score was 4.62 and the posttreatment score was 6.75, for a mean gain of 2.13 points. This difference was statistically significant,  $t(7) = 2.693$ ,  $p = .03$ . The effect size, based on the pretreatment standard deviation was 1.26, which indicates a large effect size.

The next session discussed the issues of puberty specific to adolescents with an ASD. The mean pretreatment score was 3.88 and the posttreatment score was 6.88, for a mean gain of 3.00 points. Again, this difference was found to be statistically significant,  $t(7) = 4.403$ ,  $p = .003$ . The effect size for this measure was 3.03 indicating a large effect size.

The final session covered the issue of the transition to adulthood. The mean pretreatment score was 4.38 and the posttreatment score was 6.00, for a mean gain of 1.62 points. This result was statistically significant  $t(7) = 2.489$ ,  $p = .042$ , with a large effect size of 1.08. See Table 5 for additional information.



Table 5

*Knowledge Acquisition Pre and Posttest Results*

Session Topic	M <sub>pre</sub>	SD <sub>pre</sub>	M <sub>post</sub>	SD <sub>post</sub>	<i>t</i>	<i>p</i>	<i>d</i>
IEP Development	4.62	1.69	6.75	1.49	2.69	.031*	1.26
Puberty	3.88	.991	6.88	1.64	4.40	.003*	3.03
Transition to Adulthood	4.38	1.51	6.00	1.51	2.49	.042*	1.08

*Note.* \* $p < .01$

**Qualitative Findings**

Qualitative information was collected in an effort to further the analysis of the study by looking for convergence, differences, or a combination, between the anecdotal information and the quantitative information. This information was collected using a pre and posttreatment questionnaire that were guided by the question of whether or not the web-based groups were effective in reducing stress and in providing valuable information to assist them with the nuances in parenting an adolescent with an ASD.

The qualitative analysis was completed using ATLAS.ti, a software program that assists in coding and categorizing of information leading to the generation of themes. The categories that were identified are listed in Table 6.

Table 6

*Qualitative Categories*

---

**Pretreatment**

- **Attitudes Towards Parenting Ability:**
    - Includes confidence with IEP's puberty and the transition to adulthood
  - **Attitudes Towards Overall Social Wellbeing:**
    - Includes feelings of stress, isolation, depression and lack of support
  - **Attitudes Towards Web-based Groups:**
    - Includes participants' feelings regarding previous experiences or preconceptions
- 

**Posttreatment**

- **Attitudes Towards Parenting Ability:**
    - Includes confidence with IEP's, puberty and the transition to adulthood
  - **Attitudes Towards Overall Social Wellbeing:**
    - Includes feelings of stress, isolation, depression and lack of support
  - **Attitudes Towards Web-based Groups:**
    - Includes participants' feelings of the group sessions they just completed
- 

**Pretreatment qualitative information.**

Beginning with the first category, participants had varying perceptions on their ability related to raising an adolescent with an ASD. A couple of parents felt “blessed” by their child and felt confident in their ability to manage issues related to puberty, the transition to adulthood and in working with the IEP. One parent went so far as to say that she “enjoys the IEP process.” However, the majority of the group felt confused, fearful, and inadequate in supporting their child through all of these processes. One theme that was consistent throughout many of the participants’ answers was the constant change that occurs. This appears to bring new challenges at each developmental stage requiring the

parent to again deal with the loss of an idealized child. One respondent made the following statement:

Overall, life has gotten easier the older our child has gotten. When he was younger, it was hard not to compare our child's behavior/successes with others, and his delays were so much more apparent. His practical logical way of looking at the world is a good fit for our style as parents. As we enter the teen years, it is again hard at times to see other kids being more socially engaged with their peers while he watches from the sidelines.

Regardless of their confidence levels, most parents did agree that they could benefit from additional education to better support their children through the different stages in life, especially when it is related to issues such as finances and the independence of their child.

The next category generated was the participants' attitudes towards their overall social wellbeing. This includes their levels of stress, isolation, and support. While a portion of the group felt a sense of overall social wellbeing at the onset of the study, several did state that they had experienced feelings of isolation, stress and depression as a result of raising a child with ASD. Many felt stressed due to their inadequacies as a parent. Those who felt positive about their social wellbeing appeared to have strong support systems either from family, friends, or services providers. Those who responded more negatively towards their social wellbeing appeared to lack the support from others. When asked about whom they receive support from, one participant stated, "I support myself." These parents then reported having feelings of, "...depression in the form of sadness, helplessness and lonely." These parents also felt isolated from family,

community and friends due to the behaviors and needs of their children. One parent stated,

You really just have to stop talking to other parents (or tune them out) as they have no idea. They either talk about teaching children “a lesson” or say that autism could not possibly be as bad as ADD or otherwise clueless remarks. Also, many activities are out of bounds due to sensory problems of your child or fears for their safety if they can’t be controlled.

When asked what the participants did to reduce their stress, they reported activities such as exercising, family activities, and engaging in hobbies such as crafts. Overall however, the list of stress reducing activities was short. This may be attributed to the challenge of finding care for the child while the parents attempt to engage in these activities. “Many people assume that you can just ‘get a babysitter’ even though you really need a couple of weeks in advance and \$17/hr, maybe more”.

The final category identified during the pretreatment stage was the participants’ attitudes towards groups including their previous experiences. While only three of the participants had any experience with groups, none of the participants had participated in web-based groups. Those who did have experience stated that the groups were facilitated face-to-face and were positive experiences. As to the reasons why the respondents had not participated in groups, the reasons included trouble finding groups, trouble finding childcare, and not having enough time.

When asked about the benefits and disadvantages of face-to-face groups, one responded, “You can easily connect to other parents’ problems and can get ideas on how to solve the problem, or at least get a chance to discuss it. But it is hard to get that much time and arrangement for your child.” Other disadvantages to face-to-face groups

included flexibility and convenience. However, concerns were also brought up about web-based groups and not being able to connect to others as easily and not being able to read social cues leading to misunderstandings.

#### **Posttreatment qualitative information.**

The categories remained the same during the posttreatment phase but did provide some insight into how the participants' original thoughts changed as a result of the sessions. Beginning with the first category of the participants' attitudes towards their ability to parent a child with an ASD, the comments were mixed. While some of the parents were confident in their abilities prior to the study, they indicated that they still benefitted from the topics discussed as they were able to get clarification on issues and learn perhaps more than they knew prior. Some of the participants who came into the study with low confidence levels felt as though they were more equipped to deal with the challenges regarding IEPs, puberty and the transition to adulthood. Others still felt ill-equipped and that they still needed additional information. One participant reported, "I was able to learn a few things but not many compared to the time invested."

The second category of participants' attitudes towards overall social wellbeing included mixed results as well. Many of the participants felt as though they were not dealing with feelings of isolation, depression, or stress prior to the group. Therefore, many of them did not see any change as a result of attending the group sessions. A couple of the participants indicated that they were more stressed after the sessions stating, "Right now, I'm a little more stressed just because there are some things we learned about that we have to figure out." However, the consistent theme throughout this

category was the ability to connect with others. “Yes, I do feel I received beneficial support. Even though you do not meet face-to-face, I think you connect with the group anyway”. Many of the participants indicated that they would like to continue meeting informally with each other due to the connection they felt.

Finally, the third category of the participants’ attitudes towards the web-based group is perhaps where a majority of the change occurred. It should be stated up front that the one challenge that every participant mentioned was related to technical difficulties. “The technical difficulties posed by this setting at times were frustrating: audio was choppy and I sometimes felt like I missed hearing the feedback of the facilitator”. While that appeared to be a significant issue, all of the participants stated that they would participate in another web-based group if given the opportunity. They enjoyed the ease and convenience of this type of group facilitation. One group member commented that she was sick but was still able to participate. Many of the other members mentioned that they could stay home and wouldn’t have to drive anywhere to benefit from a group. Additional comments were in regards to connecting with others who are dealing with similar issues, being able to chat with the other participants through the chat function without disturbing others, and benefitting from much needed content. Overall, the results were positive towards web-based groups.

## **Conclusion**

This chapter described the participants of the study as well as the results of the quantitative and qualitative analyses employed. First, this study had a total of 8 participants, all female, and all caregivers of an adolescent with an ASD. The

participants varied in education and varied in terms of their confidence raising a child with autism, their level of stress and their access to support. Overall, all participants returned all of the questionnaires giving insight into 8 different perspectives.

This chapter then described in detail the quantitative data obtained throughout the study. This included a pre and posttreatment stress index, and pre and posttests measuring the knowledge acquisition of each session topic. The results indicated that there was not much change in regards to stress levels but there were significant gains with regard to knowledge acquisition.

Finally, the qualitative analysis was reported indicating that six different categories were identified. (1) Pretreatment attitudes towards parenting ability (2) Pretreatment attitudes towards overall social wellbeing (3) Pretreatment attitudes towards groups (4) Posttreatment attitudes towards parenting ability (5) Posttreatment attitudes towards overall social wellbeing (6) Posttreatment attitudes towards web-based groups. There were mixed results from pretreatment to posttreatment. Respondents indicated that their stress levels were not significantly changed as a result of the session, which is congruent with the quantitative findings. There also did not appear to be a significant change in knowledge acquisition. This finding contradicts what the quantitative results showed. However, most of the respondents did indicate a positive experience and the desire to go through additional groups via the web.

## **Chapter 5: Discussion**

### **Introduction**

This chapter presents a summary of the study and conclusions drawn from the results discussed in Chapter 4. It will conclude with a discussion of the implications to the practice for those working with families of children with disabilities, limitations, and recommendations for further research.

### **Summary of the Study**

#### **Overview of the problem.**

Over the last several years, the number of children receiving the diagnosis of an Autism Spectrum Disorder has increased significantly. Currently, it is estimated that 1 in 88 children are diagnosed with an ASD (<http://www.cdc.gov/Features/CountingAutism/>). For every child affected, there are also parents who are affected. The stress, depression and anxiety experienced by parents of children with autism is higher than for parents of children with other disorders such as Down syndrome (Lee, Harrington, Louie, & Newschaffer, 2008; Donovan 1988; Holroyd & McArthur 1976). It can be assumed that parents of adolescents are especially vulnerable to higher stress due to limited services available as a result of limited research focused on the needs of this particular age group and their parents.

Autism is not isolated to families living in urban areas. There are many rural and international families who have little to no access to services to help them with issues



related to their children. This can then lead to additional feelings of isolation and depression that can impact the parents' ability to effectively parent (Schultz, Schmidt & Stichter, 2011; Connell, Sanders, and Markie-Dadds, 1997).

There are groups for parents whose children have received the diagnosis that are designed to provide support and guidance. However, many of these groups are facilitated face-to-face and are located in urban areas where the service providers work and live. For many families, including but not limited to those in rural area, challenges such as transportation, childcare, finances and time, can make it difficult to participate in face-to-face groups (Kolb, 2007). Rural families are considered to be "double disadvantaged" (Gething, 1997) as they are dealing with the significant needs of their children but without the support of others who can assist them. An example of this came from a 2001 study conducted in China where a survey revealed that 50% of children with disabilities did not receive any type of services. In 73% of those receiving services, interventions were provided by parents. As a result, the parents reported being negatively impacted, both in their personal lives and in their careers, due to the lack of resources, training and support (Wang, 2008). Additionally, many parents had to leave their work place for extended periods of time to care for their children (Wang, 2008; Lin et al., 2000).

For more than a century (Kiryakova, 2009), educators, psychologists, and other professionals have implemented various forms of distance learning programs using such technologies as letter writing (Simpson, 2009; Davidson & Birmingham, 2001), telephone (Simpson, 2009; Lester, 1995), email (Simpson, 2009; Robinson & Serfaty, 2001), radio, television, audio and video conferencing (Chute, Thompson, & Hancock, p.

24, 1999). Now with the advancements in technology and the Internet, social contact and support can be provided from virtually anywhere.

**Purpose statement and research questions.**

The question remains, can parents of adolescents with an ASD benefit emotionally and educationally from groups facilitated online? The results of this study will answer the following research questions:

1. What is the effect, based on quantitative measures, of web-based groups on their ability to:
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?
  - b. Decrease stress by providing social and emotional support to parents of adolescents with autism or a related disorder, as measured by a pre and post stress inventory?
2. What is the effect, based on qualitative information, of web-based groups on their ability to:
  - a. Increase the knowledge base of parents, of adolescents labeled with an ASD, in the following areas; stress reduction, IEP's, and puberty including the transition to adulthood, as measured by a pre and posttest?
  - b. Decrease stress by providing social and emotional support, to parents of adolescents with autism or a related disorder?

## **Overview of Results**

This research study used a mixed methods design that utilized a concurrent triangulation approach. In other words, quantitative and qualitative data were collected simultaneously and were then used to look for convergence, differences, or a combination (Creswell, 2009). Additionally, as this is a pilot study, the goal was to explore the effects of this content delivery method only, and as a result a comparison group was not used.

Beginning with the first question regarding parent stress, the quantitative data indicated little to no change while the qualitative information was mixed. Many of the parents indicated no change in stress levels as a result of participating in the study, while others reported a decrease and some, an increase. As to the second question regarding knowledge acquisition, the quantitative data were clear indicating a statistically significant gain from the pretest to the posttest for each session. However, the qualitative information was mixed as a couple of the respondents felt as though they did not learn much, while others felt that they were able to benefit from the information provided via the web-based groups. A more in-depth discussion of each of the variables is provided below with possible explanations of the mixed results.

### **Stress.**

To measure change in the participants' stress levels resulting from participation in the study, a pretreatment and posttreatment measure of stress was utilized. The Stress Index for Parents of Adolescents (SIPA) is useful in measuring stress and other negative factors associated with parenting and adolescent interaction. The answers lead to a better understanding of this relationship by investigating first, the respondent's perceptions of

the adolescent's moodiness/emotional lability, social isolation/withdrawal, delinquency/antisocial, and failure to achieve or persevere. Secondly it is helpful in understanding how the respondents view themselves in regards to their own life restrictions, relationship with spouse/partner, social alienation, and incompetence/guilt. These subscales are then used to develop a total score by which the overall stress of a parent can be measured.

The pretreatment SIPA overall indicated average levels of stress for a majority of the participants in all areas. Only two of the participants indicated above average levels of stress. This is somewhat inconsistent with what was expected due to the body of literature that suggests parents of children with an ASD are more likely to experience stress, as compared to other parents of children with or without disabilities (Lee, Harrington, Louie, & Newschaffer, 2008; Donovan 1988; Holroyd & McArthur 1976). The posttreatment then indicated that no change had occurred as a result of participating in the group sessions which would be expected knowing where the group started. If participants started the sessions with little to no stress, then they would not show much decrease in stress. What was not expected was to see those who started off with high levels of stress not showing a decrease posttreatment.

In order to better understand the quantitative data from the SIPA, pre and posttreatment questionnaires were used to collect anecdotal information providing insight into how the participants perceived changes to their stress. In analyzing the information provided by the participants regarding their stress levels, the results were mixed. While two of the participants indicated that their stress levels had decreased from pretreatment

to posttreatment, two others reported that their stress levels had increased. The remaining participants indicated no change to their overall stress levels.

There could be several reasons for the mixed results regarding stress levels. First, for the parents who did not report lower stress levels, it could be hypothesized that they did not view the content as being socially valid. The level of satisfaction that a parent perceives in terms of the effectiveness of an intervention is related to the concept of social validity, (National Autism Center, 2009) a construct that is evaluated and determined by the parent, which can greatly impact how the intervention is received and implemented. If the parent does not see the social validity, then the intervention will not be carried out as intended, reducing its effectiveness. In this case, one of the goals was to teach participants how to reduce their own stress. This included teaching them how and where to get support. In the pretreatment questionnaire, when parents were asked about who supports *them* and what services were available to *them*, many of the parents answered in terms of who supports and provides services to *their child*. This may indicate that for many of the parents, the focus, whether conscious or not, is on their children's needs and not their own needs. Perhaps if the intervention for stress were directed towards their child, they may perceive it as socially valid allowing them to implement the strategies with fidelity. Because the focus was on the parents, the strategies may not have been received well.

Secondly, a couple of the participants reported feeling more stressed on both the posttreatment SIPA and the qualitative questionnaire. One response on the questionnaire stated, "Right now, I'm a little more stressed just because there are some things we

learned about that we have to figure out”. This statement is consistent with similar studies. Kroodsma (2007) found that in studying Asperger Syndrome and parent education, several of the parents felt an increase in stress as the information they received caused them to worry more, and had feelings of guilt due to not seeking the information sooner. The findings of the Kroodsma study are similar to those found in the current study indicating that *when* the parents receive the information is as important as *how* they receive it.

Third, it is plausible that the limited effectiveness in reducing stress may be associated with the lack of time spent on addressing specific social/emotional needs. In a previous study, parents involved in a group that allowed time for supporting one another reported lower levels of depression, anxiety, and higher perceived support than parents from a comparison group in which time for support was not given (Carter, 2004; Kroodsma, 2007). The time in the current study specifically designed for support was limited to the first session. After that, the support came in the form of reactionary comments either from the facilitator or within the chat function. Unfortunately, during the first session, there were several challenges in using the technology which may have taken the focus from the topic.

Finally, as mentioned above, there were several technical difficulties that may have negatively impacted the distribution of information. The technical difficulties included problems with the audio which was choppy at times; lack of comfort with the technology which led to frustration and a lack of focus; background noise that impacted everyone’s ability to hear what was being said; and problems with individual computers

and Internet connections. While some of these issues could not be avoided, they nonetheless seemed to have a negative impact as each of the participants mentioned the technology difficulties as being a factor to their ability to benefit from the group at least once in the posttreatment questionnaire.

### **Knowledge acquisition.**

To measure the impact the web-based group sessions had on knowledge acquisition, pre and posttests were administered each week evaluating pre and post knowledge specific to the week's topic, starting with the second topic. Participants were assessed regarding the topics of IEP's, puberty, and the transition to adulthood. Pre and posttreatment questionnaires were also used asking the parents about their level of confidence with each of the topics.

After performing paired *t* tests on each of the pre-posttest pairs, the results indicated statistically significant gains for each of the topics. Based on these data, it can be assumed that the web-based groups were effective in increasing knowledge acquisition. However, the responses on the posttreatment questionnaire indicated that many of the parents felt as though they did not learn much from the sessions. Some stated that they were already comfortable with the topics prior to the sessions beginning, while others felt that factors, such as the technical difficulties, impacted their ability to benefit educationally from the sessions.

As to why the difference between the quantitative and qualitative results, first, it may have to do with perception. None of the scores were reported to the participants prior to them completing the posttreatment questionnaire. Therefore, those who reported

feeling “comfortable” with the topics were not aware of how they performed on the tests. With an average of 39 to 46 percent correct on the pretests, it appears that the participants overestimated their knowledge regarding the topics. The average correct on the posttests rose to between 60 and 68 percent indicating that there was indeed growth for the group as a whole.

Another possibility for the perceived lack of knowledge acquisition could again be attributed to perceived social validity. If parents do not perceive the information to be socially valid then they are less likely embrace the information. Callahan et al., (2008) examined the idea of social validity of a variety of interventions within an educational setting and determined that research-supported interventions were not the highest rated in terms of social validity. Interventions that required more data collection were deemed more socially valid (National Autism Center, 2009); perhaps because many parents felt confident in their data collection abilities, which then produced concrete output. In the current study, parents did not collect data themselves nor did they see any concrete data regarding their performance prior to the administration of the posttreatment questionnaire. Therefore, the responses were negative or indicated no change when there really was change.

#### **Additional results.**

While the participants indicated that they did not learn, nor was their stress reduced, they all stated that they would sign up again for a web-based group if given the opportunity. All of the participants stated that they enjoyed connecting with other parents who could understand what they were going through. This was an expected result based



on previous research that has determined parents not only gain valuable skills from educational groups, but they can also obtain emotional support through the engagement with other parents experiencing similar issues to their own (Alat, 2006; Bull, 2003). Perhaps the tools used to explore the emotional support were not sensitive enough or were not constructed well enough to detect an increase in overall social wellbeing. Nonetheless, all of the participants enjoyed the group sessions indicating that web-based groups can be effective in supporting and providing information to parents of adolescents with an ASD. The support and information gained from the groups may be different for each participant based on where they are in the journey of parenting their child.

Another finding that was expected based on extensive literature was that the parents enjoyed this group format due to the limited travel and convenience it provided. For some, finding childcare is difficult due to behavioral, communicative, and medical issues that may be present (Kolb, 2007); for others it's the travel, the time, and finances that make it challenging to participate in educational groups. A parent in the current study stated, "I loved the fact that I did not have to drive anywhere and could just be home. Also, there were no issues with childcare. I think this mode of facilitation is much less stressful." Another participant shared this thought, "I liked the flexibility that is offered in a web based group: one didn't need to travel to a site, and it allowed me to squeeze more into my day and still be available to participate at the designated time".

## Limitations

This study was not without limitations. The first limitation of this study was the small sample size and the lack of a comparison group. Initially, this study aimed to recruit 120 participants. This number was chosen based on statistical power which refers to the "...probability of rejecting a false null hypothesis" (Gliner, Morgan & Leech, 2009). In other words, it refers to the probability of making the right choice in accepting or rejecting the null hypothesis. According to Gliner, Morgan and Leech (2009) .80 is adequate power. In order to reach statistical power close to .8, the sample size needed to reach a total of 120 participants ( $N = 120$ ). A sample size of 120 ( $N = 120$ ) using a medium effect size ( $d = .50$ ) at an alpha of .05 ( $\alpha = .05$ ) would have yielded a power of .77. The groups then would have included comparison groups facilitated face-to-face and would have allowed for better information about the effectiveness of web-based groups versus face-to-face groups. However, recruitment efforts stalled due to factors beyond the researcher's control.

Information was sent to various agencies and organizations that would have contact with the population of interest. This included school districts, and state BOCES. The researcher complied with various rules that would have allowed teachers, psychologists and other service providers to disseminate the information to parents who were in need of this kind of information. However, none of the school districts or BOCES accepted the application for outside research. The denial for this particular study were either related to the topic as it did not focus on student performance or closing the achievement gap, or because the population of interest was "over-researched" and they

did not want to subject their families to additional inquiries. Barriers in accessing this population pose significant challenges for future researchers who are interested in conducting important field research. As such, careful planning and communication with schools and school districts well in advance of beginning research is highly recommended.

While these decisions were respected and not questioned, the existing research indicates that there continues to be unmet needs among the autism community. Other agencies such as Developmental Pathways, the ARC of Colorado, and the Joshua School, a school designed for children with autism, were very excited to pass along this information. This suggests that perhaps researchers and other advocates for the autism community, and for children with other disabilities, need to communicate with and assist local school districts and school leaders in understanding the needs of these children and their parents. In the end, a pilot study with one group was determined to be a step in the right direction and to help guide future research.

Another limitation of this study involves the characteristics of the participants. The research indicates that families living in rural communities are most at risk for depression, isolation and other negative factors related to raising a child with an ASD due to the limited access they have to services (Symon, 2001). Because of the difficulties in recruitment efforts, the participants who eventually signed up and completed the study were not part of the population of interest. The initial population of interest included parents from rural communities who have had limited access to services. Each of the participants in this study lives in urban areas and has had access to numerous services and

support systems. A couple of the participants actually were members of groups or organizations that advocate for and provide services to families of children with an ASD. The characteristics of this particularly well connected group may have impacted the results in regards to stress. Because they were well connected prior to the study, their stress levels were perhaps lower than those not so connected. Therefore, the results may be somewhat misleading and not generalizable. The final limitation for this study is the lack of participation from fathers. All participants were mothers, or female caregivers. Kroodsma (2007) suggests that fathers of children need more encouragement to participate in parent education programs. This was based on research conducted by Sofronoff and Farbotko (2002) who noted that many fathers with children on the spectrum also have traits similar to their children. These fathers then have difficulty assimilating and talking to others in group settings. It can be hypothesized then that if fathers had participated in this group, there may have been more of an impact on knowledge acquisition as the fathers may not been as involved historically as the mothers, therefore, needing additional information to assist with their child.

### **Implications for Future Research**

Face-to-face groups continue to be the “gold standard” in providing education and support. However, with advances in technology along with the concept of social presence, web-based groups for parents of children with disabilities can be utilized to provide services for those who don’t have access to face-to-face groups. In the current study some of the perceptions were negative regarding the benefits related to reducing stress and increasing knowledge. However, valuable benefits were also identified

indicating this as an area that is worth researching further. With minor changes, similar studies could successfully guide service providers in the development and implementation of beneficial programs that will support and educate a community of people who have a dire need for this type of service.

One of the main issues that continues to arise among computer-mediated groups include feeling socially disconnected (Slagter van Tryon, & Bishop, 2009; Haefner, 2000; Menchaca & Bekele, 2008; Reisetter & Boris, 2004), and a lower level of trust with the information that is being presented or “posted” (Coulson & Knibb, 2007). One of the main goals of this project was to provide an environment where participants could feel connected without being in the same room. However, the technology appeared to have interfered with the establishment of effective social presence. With this in mind, it is recommended that future research in this area take the extra steps to eliminate, or limit, the interruptions caused by the technology. This may include spending one complete session on how to use and get comfortable with the environment. Although the researcher may be comfortable with using computers, the characteristics of the participants must be considered. For example, research indicates that parents of lower SES categories are less likely to attend parent education groups (Smith, Gabard, Dale, & Drucker, 1994; Cleve, 1989). Traditionally, higher SES individuals have been the primary users of the Internet for informational purposes. While lower SES groups are increasing their use of the Internet, there could potentially be issues with their comfort level when it comes to using the Internet for informational purposes. Therefore, lower

SES groups who may benefit from a web-based group may need additional support and guidance with the technology.

In the current study, several of the participants stated that once they were comfortable with the computer mediated environment, they were able to benefit from the topics and the group discussion. One participant summed it up this way,

The content of the program was excellent and the only complaints I have are related to technical difficulties. I suspect each participant was using different equipment to access the web and as a group, we are not necessarily a technologically savvy population (our kids are, though?!) so for anyone considering developing such a program, they would want to have a plan in place to assist and support participants who are experiencing technical difficulties.

To avoid these issues, one recommendation is to devote the first session to learning about the technology. Once this is complete, the group can then focus on the material to be presented without the interference and frustration related to technology.

Once the members of the group are comfortable and able to move on to the content, it is recommended that an extensive amount of time be provided for intentional and deliberate conversations about stress and social/emotional needs. While it is important to provide education to parents of children with an ASD, their emotional needs must not be overlooked. The stress, depression and anxiety experienced by parents of children with autism is higher than for parents of children with other disorders such as Down syndrome (Lee, Harrington, Louie, & Newschaffer, 2008; Donovan 1988; Holroyd & McArthur 1976). This stress can then impact their effectiveness as a parent and as a service provider. Research indicates that participants in groups are more likely to accept and utilize new information if they also feel socially and emotionally supported (National

Autism Center, 2009) Once the social validity is established and the stress is reduced, then the parent can absorb information more effectively thereby providing better support for their children.

While this pilot study was important in creating a foundation for future studies of this kind, studies including a larger sample size and perhaps a comparison group will be crucial in adding to the internal and external validity. In order to accomplish this, special attention needs to be given to recruiting appropriate participants for the study. Due to the significant difficulties of recruiting through school districts, other options should be explored. This may include direct contact with local and national organizations to help promote the study and advocate for those who could benefit from its content. Another option may include networking within the autism community to help spread the word. This can be done through special events, organizations or web-based communities that provide information and services to individuals and families of children with autism.

A final recommendation involves the practice of the school psychologist. Taking into account the incidence rate of ASDs, and the prevalence of other disabilities, it may be in the best interest of the school psychologist to provide training to parents at each transitional level. This “expected” program can provide parents with much needed information that relates to the specific developmental needs of his/her child. Not only will this bridge the gap that sometimes exists between parents and the school, but also will grant access to parents who may not otherwise ask for, or have access to in the larger community setting. These parent training programs can be provided using the technology

discussed in this study, allowing for an efficient and cost-effective means of providing preventative, research-based information to parents of children with disabilities.

## **Conclusion**

This chapter provided a discussion of the results as they relate to the research questions, the limitations, and guidance for future research. While the results were mixed, this study did find that web-based groups can be effective in providing education and support to parents who do not have access to any other services. It also identified areas for improvement so that more effective programs can be researched and developed. With 1 in 88 children diagnosed with an ASD (<http://www.cdc.gov/Features/CountingAutism/>), it is imperative that more efficient and effective services be developed to support all of the families affected by this disorder; not just the ones we have access to or who has access to us. While the partnership between parents and service providers is crucial for the child, it is also crucial for the parents.



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## Appendix A

### Recruitment Letter

Dear Parent,

You are invited to participate in a study that aims to address the specific needs of parents of adolescents with Autism Spectrum Disorders (ASD), who may not otherwise have access to support and guidance. As a parent of an adolescent with an ASD, you face unique challenges that many other parents may not understand. You also understand the lack of accessible resources to address those unique needs as you begin to navigate the confusing and stressful world of adolescence.

I am a doctoral student in the Child, Family and School Psychology program at the University of Denver, researching the benefits of groups, designed for parents of adolescents with autism, facilitated via the Internet versus those facilitated face-to-face. The results of this study may lead to more widespread use of videoconference technology giving access to families who may otherwise have limited access to resources, such as those living in rural communities.

Groups will be offered using videoconference or web-based technology. The content of group sessions includes stress management, IEP fundamentals, issues related to puberty specific to adolescents with ASD, and the transition to adulthood. This information will be provided in four 1 ½ hour sessions, and facilitated by a knowledgeable and experienced graduate student from the University of Denver.

You will only be required fill out a variety of questionnaires and tests, before and after the group sessions, in an effort to assess your knowledge, as well as your stress levels prior to and after the sessions. This data will then be used to explore the social/emotional and educational benefits of groups facilitated using the web.

If you have access to a computer and the Internet, and are a parent of an adolescent with an ASD, then you may be eligible for participation in this study. For more information, feel free to contact me at [ericzimmerman38@gmail.com](mailto:ericzimmerman38@gmail.com).

Sincerely,

Eric Zimmerman, Ed.S., NCSP

## Appendix B

### Social History

Please fill out this brief social history form. It is intended to provide the investigator with background information that will be used for data comparison purposes as well as to ensure consistency among participants. Personal information reported here will only be used for organizational purposes and will be kept confidential.

**Name:**

#### Family History

Child is living with: ☐ Both Parents ☐ Mother ☐ Father ☐ Mother and Stepfather  
☐ Father and Stepmother

Is the child adopted? ☐ Yes ☐ No

Status of parents' marriage: ☐ Married How long?  
☐ Separated ☐ Divorced ☐ Widowed ☐ Single

Where does the participating parent/s live? (Please include city and county)

Who referred you to this study?

What services have you received to assist you in parenting a child with an ASD and from whom?

#### Mother

#### Father

Age:

Age:

Highest Grade Completed:

Highest Grade Completed:

Occupation:

Occupation:

Leisure Activities:

Leisure Activities:

Does the participating parent/s have a support system and who provides that support?

#### Child's Profile

Child's Birth Date:

Child's Grade:

Gender:

Please provide information regarding the child's diagnosis: (autism, HF autism, Asperger Syndrome, Rett Syndrome, PDD, etc.)

Cognitive Functioning (Please give scores if available):

Adaptive Functioning (Please give scores if available):

What services is your child receiving (OT, PT, Speech, etc.) and from whom:

Present Personality and Behavior (Please circle all that apply)

Sad	happy	leader	follower	moody	friendly	
	quiet	overactive	independent	dependent	sensitive	affectionate
fearful		cooperative	tantrums	lethargic	too responsible	
	trouble sleeping		hard to discipline	even-tempered		prefers to be
alone						

Are there other children in the home? (Include age and gender)

Do the other children have any disabilities? (Please describe)

## Appendix C

# SIPA

### Stress Index for Parents of Adolescents

Peter L. Sheras, PhD, and Richard R. Abidin, EdD

**ID:**

**Date:**

This questionnaire contains 112 statements. Read each statement carefully. Please focus on the adolescent you are currently concerned about (which for this study is your child/children with ASD), and circle the response which best represents your opinion.

**For statements 1-90,**

Check SD if you *strongly disagree* with the statement.

Check D if you *disagree* with the statement.

Check NS if you are *not sure* how you feel about the statement.

Check A if you *agree* with the statement.

Check SA if you *strongly agree* with the statement.

**For statements 91-112,**

Check Y for "Yes."

Check N for "No."

Although you may not find a response that exactly states your feelings, please check the response that comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Check only one response for each statement, and respond to all statements. Questions about your "spouse or partner" refer to your husband or wife, or other parenting partner (i.e., the other person who is most involved in the parenting of your child). If you do not currently have a spouse or partner, leave these items blank. Additionally, the term "Teenager" is a general term and still applies to your child even if they are not yet a true teen.

1. My child has sudden changes of feelings or moods

SD\_\_\_

D\_\_\_

NS\_\_\_

A\_\_\_

SA\_\_\_

2. My child has many friends

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

3. My child has never been in trouble with the police

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

4. My child does his or her best in school

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

5. My child shows affection toward me

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

6. My child becomes very upset or angry when he or she does not get his or her own way

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

7. My child has little or no energy

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

8. My child has become physically violent

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

9. My child seems motivated to work hard

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

10. My child talks to me about problems

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

11. My child has a negative attitude

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

12. It bothers me that my child is so quiet

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

13. I think my child steals things

- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
14. My child does poorly in school
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
15. My child tells me where he or she is going
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
16. My child is grouchy and irritable
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
17. My child has no close friends
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
18. My child is always telling lies
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
19. My child must get a great deal of attention in order to work well
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
20. My child stays out too late at night
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
21. My child has a bad temper
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
22. My child is no liked by other children the same age
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
23. My child has done serious damage to our home
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|
24. My child gives up easily
- |  |       |      |       |      |       |
|--|-------|------|-------|------|-------|
|  | SD___ | D___ | NS___ | A___ | SA___ |
|--|-------|------|-------|------|-------|

25. My child has the same moral values that I have

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

26. My child seems very moody

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

27. My child is frequently bossed around or bullied by others

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

28. My child respects the property of others

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

29. My child could do better in school by trying harder

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

30. I believe that my child drinks more alcohol than I would like

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

31. My child gets upset over little things

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

32. My child is shy with others of the same age

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

33. I believe that my child skips school

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

34. My child completes the tasks he or she starts

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

35. My child avoids me at home

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

36. My child yells at me or my spouse/partner

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

37. My child gets teased a lot and it bothers me

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

38. My child has threatened to hurt people

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

39. My child has a short attention span

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

40. My child likes to do things with the whole family

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

41. My child thinks I am unfair

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

42. My child never seems to do anything

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

43. My child is disobedient at school

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

44. I worry that my child does not do his or her school work

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

45. My child does things for me that make me feel good

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

46. My child argues too much

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_



47. I often wonder if my child is lonely

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

48. My child often gets in trouble when he or she is with his or her friends

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

49. My child puts forth a lot of effort to reach his or her goals

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

50. My child thinks I do not love him or her

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

51. Since having a teenager, I have a lot fewer chances to see my friends and to make new friends

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

52. Since having a teenager, I don't seem to spend as much time with in-laws and relatives as I would like

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

53. I feel alone and without friends

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

54. I am usually a positive and cheerful person

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

55. Since my child became a teenager, my spouse/partner and I don't spend as much time together as a couple as I had expected

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

56. I find myself giving up more of my life to meet my child's needs than I ever expected

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

57. I often have the feeling that other people my own age don't particularly like my company

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

58. When I go to a party, I don't expect to enjoy myself

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

59. Having a teenager does not leave me enough time for my own friends

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

60. My spouse/partner often hurts my feelings

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

61. I can't make decisions without help

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

62. I often feel guilty after I get angry at my child

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

63. Since my child became a teenager, my spouse/partner and I have been less physically affectionate than I would like

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

64. Having a teenager has caused more problems than I expected in my relationship with my spouse/partner

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

65. I often feel "left out" when I am around other people

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

66. I feel that I am an excellent parent

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

67. Since my child became a teenager, I feel that I am almost never able to do things that I like to do

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

68. I often need to work hard to avoid conflict with my spouse partner

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

69. I am as capable as most other parents I know

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

70. I often have the feeling that I cannot handle things very well

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

71. Since my child became a teenager my spouse/partner distrusts my judgment as a parent

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

72. My spouse/partner distrusts my judgment as a parent

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

73. Since my child became a teenager, my spouse/partner has not given me as much help and support as I expected

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

74. When I think about myself as a parent of a teenager, I believe I can handle anything that happens

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

75. Since my child became a teenager, my sexual relationship(s) has (have) been less satisfying

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

76. I frequently argue with my spouse/partner about how to raise my child

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

77. I don't have anyone who listens to my frustrations

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

78. I feel every time my child does something wrong it is really my fault

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

79. I felt sadder and more depressed than I expected when my child became a teenager

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

80. My spouse/partner and I disagree on the best way to discipline my child

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

81. I can talk to my spouse/partner about anything

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

82. When my child does things that bother me on purpose, I don't know what to do

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

83. It is easy for me to understand what my child wants or needs

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

84. I expected to have closer and warmer feelings for my child at this age than I do

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

85. My child comes to me for help more than to other people

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

86. When I think about the kind of parent I am I often feel guilty or bad about myself

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

87. I am usually successful at getting my child to do what I ask

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

88. I enjoy being the parent of a teenager

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

89. I cannot get my child to listen to me

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

90. When my child misbehaves or get in trouble, I feel responsible as if I didn't do something right

SD\_\_\_ D\_\_\_ NS\_\_\_ A\_\_\_ SA\_\_\_

For statements 91-112, please check Y for "Yes" or N for "No."

During the last 12 months, have any of the following events occurred in your immediate family?

91. Divorce

Y\_\_\_ N\_\_\_

92. Marital reconciliation

Y\_\_\_ N\_\_\_

93. Marriage

Y\_\_\_ N\_\_\_

94. Separation

Y\_\_\_ N\_\_\_

95. Pregnancy

Y\_\_\_ N\_\_\_

96. Other relative moved into household

Y\_\_\_ N\_\_\_

97. Went deeply into debt

Y\_\_\_ N\_\_\_

98. Income increased substantially (20% or more)

Y\_\_\_ N\_\_\_

99. Moved to new location  
Y\_\_\_\_ N\_\_\_\_
100. Promotion at work  
Y\_\_\_\_ N\_\_\_\_
101. Income decreased substantially  
Y\_\_\_\_ N\_\_\_\_
102. Alcohol or drug problem  
Y\_\_\_\_ N\_\_\_\_
103. Death of close family friend  
Y\_\_\_\_ N\_\_\_\_
104. Began new job  
Y\_\_\_\_ N\_\_\_\_
105. Entered new school  
Y\_\_\_\_ N\_\_\_\_
106. Trouble with superiors at work  
Y\_\_\_\_ N\_\_\_\_
107. Trouble with teachers at school  
Y\_\_\_\_ N\_\_\_\_
108. Legal problems  
Y\_\_\_\_ N\_\_\_\_
109. Death of immediate family member  
Y\_\_\_\_ N\_\_\_\_
110. Demands/illness of aging parent

Y\_\_\_\_ N\_\_\_\_

111. Serious injury or medical problem

Y\_\_\_\_ N\_\_\_\_

112. Continuing or chronic medical condition (diabetes, heart disease, etc.)

Y\_\_\_\_ N\_\_\_\_

*Note: This format is only being used in this study to simplify the process of obtaining information from participants who are involved with this study. Each of the participants' answers will be transferred to individual SIPA protocols and will be scored according to directions provided in the manual.*

## **Appendix D**

### **Pre and Posttreatment Qualitative Questionnaires**

#### **Pretreatment Qualitative Questionnaire**

1. Please describe your experience of being a parent of a child with an Autism Spectrum Disorder.
2. Do you feel that you have had adequate access to services to support you in your parenting role of a child with autism?
3. What services/education have you received in the past to support you as a parent of a child with an autism spectrum disorder?
4. Has access to services for you or for your child changed since early childhood? In what ways?
5. What services, education, programs are lacking for you now that your child is an adolescent?
6. What services, education, programs are lacking for your child now that they are an adolescent?
7. Please describe any feelings of isolation as a result of being a parent of a child with autism. Are there any activities that you have had to stop due behaviors, responsibilities, medical concerns, etc?
8. Please describe any feelings of depression you may have experienced that may be related to the challenges of raising a child with a disability?



9. Please describe the stress related to parenting a child with an autism spectrum disorder?
10. How equipped do you feel as a parent of an adolescent with an autism spectrum disorder?
11. What information do you feel you need as a parent of an adolescent with an autism spectrum disorder?
12. Have you participated in a face-to-face parent group before? If yes, please describe your experience, the format of the group, and the purpose of the group.
13. If you have not participated in a face-to-face group before, what have been the reasons?
14. Have you participated in a web-based parent group before? If yes, please describe your experience, the format, and the purpose of the group.
15. Have you participated in a face-to-face and a web-based group before? If yes, which do you prefer and why?
16. Regardless of your experiences, what are the benefits of face-to-face groups? What are the disadvantages?
17. Regardless of your experiences, what are the benefits to web-based parent groups? What are the disadvantages?
18. Who do you currently rely on for support and assistance for your child's needs?

19. Who do you currently rely on for support for your needs?
20. What do activities do you currently do to relieve your stress?
21. How supportive do you believe other parents with adolescents with autism can be to you?
22. Describe your confidence as it relates to the IEP process/educational needs? Does your stress level increase when the time is approaching to meet again with the school based team? Describe your experiences thus far in dealing with your child's IEP and/or educational career.
23. How knowledgeable are you about the topic of puberty as it relates to children with ASD? Are you comfortable in having the difficult conversations and addressing some of the behaviors that go along with this period in life? Please describe your experiences thus far in dealing with puberty.
24. How knowledgeable are you about the transition to adulthood as it relates to your child? Do you feel prepared and informed of what is available to you and your child financially, educationally, etc.?

### **Posttreatment Qualitative Questionnaire**

1. Describe any changes in feelings of isolation compared to the beginning of the group sessions.
2. Describe any changes in feelings of depression compared to the beginning of the group sessions.
3. Describe any changes in your level of stress compared to the beginning of the group sessions.
4. Do you feel that the changes to any of the feelings listed above are a result of the group sessions? Why or why not?
5. How equipped do you feel now in dealing with issues related to puberty? How does this compare to the beginning of the group?
6. How equipped do you feel now in dealing with your child's IEP? How does this compare to the beginning of the group?
7. How equipped do you feel now in dealing with the transition to adulthood? How does this compare to the beginning of the group?
8. Although you did not meet face-to-face, do you feel that you received beneficial emotional/social support? Why or why not?
9. Although you did not meet face-to-face, do you feel the group was effective in providing information? Were you able to learn effectively through this mode of facilitation? Why or why not?
10. What challenges did you encounter related specifically to the mode of facilitation of the group?

11. What did you enjoy about the mode of facilitation?
12. Would you consider participating in another group facilitated using the web? Why or why not?
13. Please provide any other information useful to others who may be interested in developing similar programs using the internet to provide services to parents of children with disabilities.

## Appendix E

### Group Session Content Tests

ID#:

Date:

#### IEP Test Questions:

Please choose the BEST answer to the questions below.

1. How many calendar days does a school have to complete assessments?  
**A. 60**  
B. 30  
C. 90  
D. None of the Above
2. What category of the assessment process includes measurement of independent functioning in the areas of self-care, social functioning, community safety, on the job functioning, and independent living?  
A. Social Emotional Assessment  
B. Cognitive Assessment  
**C. Adaptive Assessment**  
D. Transitions Assessment
3. What category of the assessment process includes measurement of processing abilities such as memory, speed of processing, verbal and nonverbal reasoning?  
A. Communication  
**B. Cognitive**  
C. Achievement  
D. Executive Functioning
4. When qualifying for an IEP for an ASD, three characteristics must be documented. They include:  
Qualitative impairment in communication; *and*  
Restricted repetitive and stereotyped patterns of behavior, interests, and activities  
What is the third characteristic that must be documented?  
A. Qualitative impairment in cognitive functioning  
B. Qualitative impairment in adaptive functioning  
**C. Qualitative impairment in social interaction**  
D. Qualitative impairment in social emotional functioning
5. At what age do post-secondary considerations have to legally begin?  
A. 12  
B. 13  
C. 14  
**D. 15**

6. *Changes made to instruction or the curriculum that fundamentally changes what the child is expected to learn. Examples include providing instruction to the child at a different academic level or testing him on different knowledge or skills than other students in the class.* This is the definition of a/an
- A. Modification**
  - B. Accommodation
  - C. Goal
  - D. Objective
7. A/an \_\_\_\_\_ is used to develop a BIP
- A. Social/emotional evaluation
  - B. Functional Behavior Assessment**
  - C. Cognitive evaluation
  - D. Adaptive evaluation
8. What law governs the IEP process?
- A. CDE
  - B. IDEA
  - C. ADA
  - D. IDEIA**
9. During an evaluation of a child with ASD, a/an \_\_\_\_\_ is critically important.
- A. Social functioning
  - B. Behavioral Interventions
  - C. Developmental perspective**
  - D. None of the above
10. Annual goals must be:
- A. General
  - B. Limited
  - C. Measurable**
  - D. Time sensitive

**ID#:**

**Date:**

**Puberty Test Questions:**

Choose the BEST answer for each question below

1. What percentage of adolescents experience an increase in seizure activity during puberty?  
A. 10  
B. 15  
**C. 25**  
D. 35
2. According to Sicile-Kira which one below is NOT a consideration when determining when, where, and how to have conversations regarding puberty and sex?  
A. Child's maturity Level  
B. Child's emotional maturity Level  
**C. Child's acting out behaviors**  
D. Child's chronological age
3. For girls, puberty begins as early as  
**A. 8-9**  
B. 10-11  
C. 12-13  
D. 14-15
4. For boys, puberty usually begins at age  
A. 8-9  
**B. 10-11**  
C. 12-13  
D. 14-15
5. Precocious puberty is \_\_\_\_ times higher in teens with ASD  
A. 10  
**B. 20**  
C. 30  
D. 40
6. Neurotypical teens display more emotional maturity through their interest in  
A. The opposite sex  
B. Risk taking behavior  
C. Independence  
**D. All of the above**
7. Sexual drives have to be moderated by  
A. Parents  
**B. Responsibility**  
C. Education

- D. Self-control
8. Dr. Koegel recommends what for explaining appropriate and inappropriate touch:  
**A. Social circles**  
B. Social interaction  
C. Social groups  
D. Social gatherings
9. It is recommended that which issue, specific to ASD, be discussed during puberty  
A. Modesty  
B. Stalking  
C. Abuse Prevention  
**D. All of the above**
10. Sicile-Kira recommends you do what for discussing feelings with your teen  
A. Music  
**B. Draw**  
C. Feelings book  
D. Talk



**ID#:**

**Date:**

**Transition Test Questions:**

Choose the BEST answer for the questions below

1. When conducting a transitions assessment, there should be a shift from what is missing in a student's developmental profile to what skills are necessary for the student to be successful such as Preferences, Strengths, Work habits and
  - A. Progress
  - B. Desires
  - C. Interests**
  - D. None of the above
2. According to Dr. Rick Blumberg, author of *Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger's Syndrome*, parents should apply for services from the Department of Vocational Rehabilitation no later than:
  - A. Sophomore year
  - B. Junior year**
  - C. Senior year
  - D. After graduation
3. 504's are governed by
  - A. CDE
  - B. IDEA
  - C. ADA**
  - D. IDEIA
4. When considering transitions, the team should consider education, independence, employment, legal issues, and
  - A. Medical
  - B. Cognitive
  - C. Leisure**
  - D. Financial
5. SSDI refers to
  - A. Supplementary Income
  - B. Supplementary Insurance**
  - C. Support for Independence
  - D. None of the above
6. The transition assessment is considered
  - A. A process**
  - B. An event

- C. An evaluation
  - D. A senior activity
7. By end of \_\_\_\_ grade a discussion of whether college is still part of the vision should be had.
- A. 9<sup>th</sup>
  - B. 10<sup>th</sup>**
  - C. 11<sup>th</sup>
  - D. 12<sup>th</sup>
8. The Person Centered Plan is used to
- A. Compare vision to current events
  - B. Illustrate the action plan for the next stage in life
  - C. Guide future planning
  - D. All of the above**
9. Assessing the ability to make choices, select goals, and develop a plan to achieve those goals is referred to as
- A. An adaptive assessment
  - B. A cognitive assessment
  - C. A self-determination assessment**
  - D. An executive functioning assessment
10. When considering colleges, location, cost, services, requirements, campus life and \_\_\_\_ should be considered
- A. Size
  - B. Difficulty
  - C. Reputation
  - D. Course of study**

## Appendix F

### Group Session Curriculum Slides

# SESSION 1

## Stress Reduction



IT'S OK...TAKE TIME FOR  
*YOU!*

*Lower stress levels and anxiety levels lead to increased positive parenting practices (Shultz et al., 2011; Connell, Sanders, & Markie-Dadds, 1997).*

### Stress Reduction Kit



Directions:

1. Place kit on FIRM surface.
2. Follow directions in circle of kit.
3. Repeat step 2 as necessary, or until unconscious.
4. If unconscious, cease stress reduction activity.

ANAJOKES.COM

We know that this information is common sense but sometimes you need to be reminded; sometimes you need permission, especially when raising a child with a disability. It is ok to take time for you! In fact, lower stress and anxiety levels leads to increased positive parenting practices (Schultz et al., 2011; Connell, Sanders, and Markie-Dadds, 1997).

## GROUP DISCUSSION



- *Stress?*
- *Isolation?*
- *Grief?*
- *Confusion?*
- *Anger?*

- What has been your experience, negative and positive? How do you define stress? How do you cope?

Group Share - Parenting a child with any disability can be difficult. However, parenting a child with an autism spectrum disorder can be especially strenuous due to the multitude of behaviors and needs of these children. This can result in parental stress, isolation, grief, confusion, and anger. However, each parent is as unique as their ASD child and there is no “profile” for the parent of a child with autism. Some parents experience all of these feelings, some feel none of them. What you do have in common is that you want the best for your son or daughter. So, what is your experience in raising your child, negative and positive? How do you cope?

## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd



- **“The Freezer Tip”**
  - **Keep yourself stocked up**
  - **The more you give, the less you have to give over time... need time to “re-stock”**

*Tips for Looking After Yourself* – In her book, *Parenting a Child with Asperger Syndrome*, author and mother of a son with Asperger Syndrome, Brenda Boyd shares valuable tips for taking care of the caretaker. Some of them are self-explanatory while others need a little explanation.

Keep yourself stocked up – Boyd calls this the “Freezer Tip”. The premise behind this tip is that you start off being “stocked” but the more you give, the less you have to give over time. At some point, you need to do something for yourself in order to “re-stock”.

## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd

- **Get Plenty of  
Support**



Get plenty of support – Don't feel as though you have to go through this alone. This support can come from family members, friends, or others who may also have a child with autism. There are plenty of online groups you can join or talk with others at your child's school. Even individual counseling can be helpful from time to time.

## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd

- **Don't take things personally**
- **Don't neglect other areas of your life**



Don't take things personally!

Don't neglect other areas of your life – This includes work AND play. Don't allow yourself to forget that it's okay to have fun once in a while. Find simple pleasures that don't take a lot of time and effort. Spend time on your relationships, your spiritual life, and YOU! Remember, you need to remain stocked up!



## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd

- *Be realistic about tackling problems!*



Be realistic about tackling problems – You can't solve everything all at once, and you simply can't solve EVERYTHING! Prioritize and don't sweat the small stuff. And, delegate! Use those around you who can and are willing to help.

## TIPS FOR LOOKING AFTER YOURSELF

*Parenting a Child with Asperger Syndrome*

By Brenda Boyd



## Give yourself SMART goals

- *Small*
- *Measurable*
- *Achievable*
- *Realistic*
- *Time based*

Give yourself SMART goals – These goals can be useful when trying to make progress in any area, whether for your child or for yourself. SMART stands for:

Small

Measurable

Achievable

Realistic

Time based

\*We will do more with this later

## TIPS FOR LOOKING AFTER YOURSELF

*Parenting a Child with Asperger Syndrome*

By Brenda Boyd



Let Strategies be  
“on tap” not “on top”

- *Be flexible*
- *Try things out*
- *Don't be afraid of changing strategies*
- *Take control... don't let strategies control you!*

Let the strategies be “on tap” not “on top” – This tip refers to being flexible with strategies. Try things out and don't be afraid the change strategies or go back to old strategies. You take control don't let the strategies control you!

## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd



- **Try not to spoil your child 😊**
  - **Don't lose sight of your expectations.**

Try not to spoil your child – There is a difference between supporting and enabling. As parents we want to protect our children but in the end we may doing more harm than good. Let them fail and struggle in order to allow for learning. If you lose sight of your expectations, so will your child and those who work with your child. When you have to step in to help, make sure you do it in a way that doesn't take the power away from your child or those who work with them. That makes it difficult for everyone to learn and puts more pressure on you!

## **TIPS FOR LOOKING AFTER YOURSELF**

*Parenting a Child with  
Asperger Syndrome*

By Brenda Boyd



- **Find someone to talk to**
- **Let yourself off the hook**
- **Mind over matter**

# **REMEMBER... TAKE CONTROL!**

*Be mindful of your stress and anxiety. Not  
acknowledging it doesn't make it go away!*

Remember, be mindful of your stress and anxiety. Not acknowledging it doesn't make it go away. Take control! It's ok, you have permission!  
Spend some time with yourself and be aware of the stress in your body. Figure out where the stress is coming from and do something about it.

## YOGA... IT'S NOT FOR EVERYONE



- Find ways to reduce your stress that work for YOU!
- Keep it simple
  - Read a book
  - Go for a walk
  - Spend time in your garden
  - Keep yourself “stocked up”

Yoga...it's not for everyone - Reducing your stress does not have to be some trendy activity or the latest craze on the internet. Keep it simple! Read a book, go for a walk, or spend time in your garden. It may not be easy to get this time away from your responsibilities related to parenting, but this is where you enlist the help of others. Asking your spouse, significant other, family, or friends whom you trust to give you 30 minutes enables you valuable time to take care of you and to “keep yourself stocked up”.



## GROUP SHARE



- What thoughts do you have regarding the tips listed above?
- What kinds of things can you do to reduce your stress?
- What are the challenges to making this happen?
- How do you overcome those challenges?



## INDIVIDUAL WORK

### SMART Goals

- *S – What is your goal? (Remember, start Small)*
- *M – How will you Measure your goal?*
- *A – Explain how your goal is Achievable and how you will go about achieving your goal. If you find your goal is not achievable, you may want to write a new goal.*
- *R – How realistic is your goal?*
- *T – When can you reach your goal?*

One way to take control is to create goals. Using what you learned about SMART goals, take time to create a SMART goal for your stress. Again, SMART goals are small, measureable, achievable, realistic and time-based. If you make a goal to reduce your stress level, your SMART goal might state that you will have run 5 miles by this time next week. Start small to increase the likelihood of success! Take time to fill out your SMART goal form. We will check in with each other throughout the course of this program. Each week, you can update us on your progress. Once you are finished writing your SMART goal, we will share with the group.

## SMART Goal

**S** — What is your goal? (Remember, start Small)

--

**M** — How will you Measure your goal?

--

**A** — Explain how your goal is Achievable and how you will go about achieving your goal. If you find your goal is not achievable, you may want to write a new goal.

--

**R** — How realistic is your goal?

--

**T** — When can you reach your goal?

--

## **Session 2**

### **IEP's: 101**

The Middle and High School Years

### **The Good...**

- Renewal
- Anticipation
- Hope
- Excitement



### **The Not So Good...**

- Fear
- Confusion
- Anxiety
- Starting Over



**The Middle and High School  
Years**

- What have your experiences been, good and bad?
- What are your concerns?
- What are you looking forward to?
- What questions do you have?



**Group Share**

A	T	J	M	X	J	X	W	X	F	D	P	E	M	H
Z	C	Y	J	B	H	T	D	H	Y	A	B	V	O	V
I	S	C	Q	V	A	D	W	T	R	I	J	S	D	J
U	I	B	O	I	P	B	H	T	S	E	I	M	I	Y
Q	M	I	Q	M	N	R	I	E	J	D	M	Y	F	E
V	N	P	I	M	C	S	K	P	I	M	X	I	X	
B	L	A	X	I	O	P	P	Q	Y	U	A	C	J	
Y	J	V	R	P	C	D	B	T	E	A	E	A	Y	
F	J	E	A	D	N	A	J	A	O	T	I	Y	T	B
W	P	N	T	S	Y	O	S	O	T	S	T	L	I	L
T	I	B	L	I	D	E	A	I	S	I	M	Q	O	T
S	E	A	I	K	A	Z	H	T	I	F	O	S	N	I
W	O	J	Z	L	A	R	D	C	F	D	X	N	S	N
G	U	T	F	S	K	S	A	B	A	F	X	T	S	J
S	E	V	I	T	C	E	J	B	O	A	D	F	Q	S

**IEP BASICS**

- Procedural Manual: The Colorado State Recommended IEP
- Colorado Department of Education
  - [http://www.cde.state.co.us/cdesped/IEP\\_Eng.asp](http://www.cde.state.co.us/cdesped/IEP_Eng.asp)



**IEP Basics**

- **Similarities Between IDEA and IDEIA**
- Much of the original verbiage and regulations set forth in IDEA 1997 remain in IDEIA. Children with disabilities or suspected disabilities are still eligible for evaluation through the school system at no cost to the parent.

**IDEA vs. IDEIA**



- **Similarities Between IDEA and IDEIA**

- Public school systems must still provide an IEP for students with disabilities when warranted. Certain forms, reporting documents, and other administrative duties remain the same. Parents' consent is still a primary focus with regard to IEP meetings, changes and educational interventions.

## **IDEA vs. IDEIA**

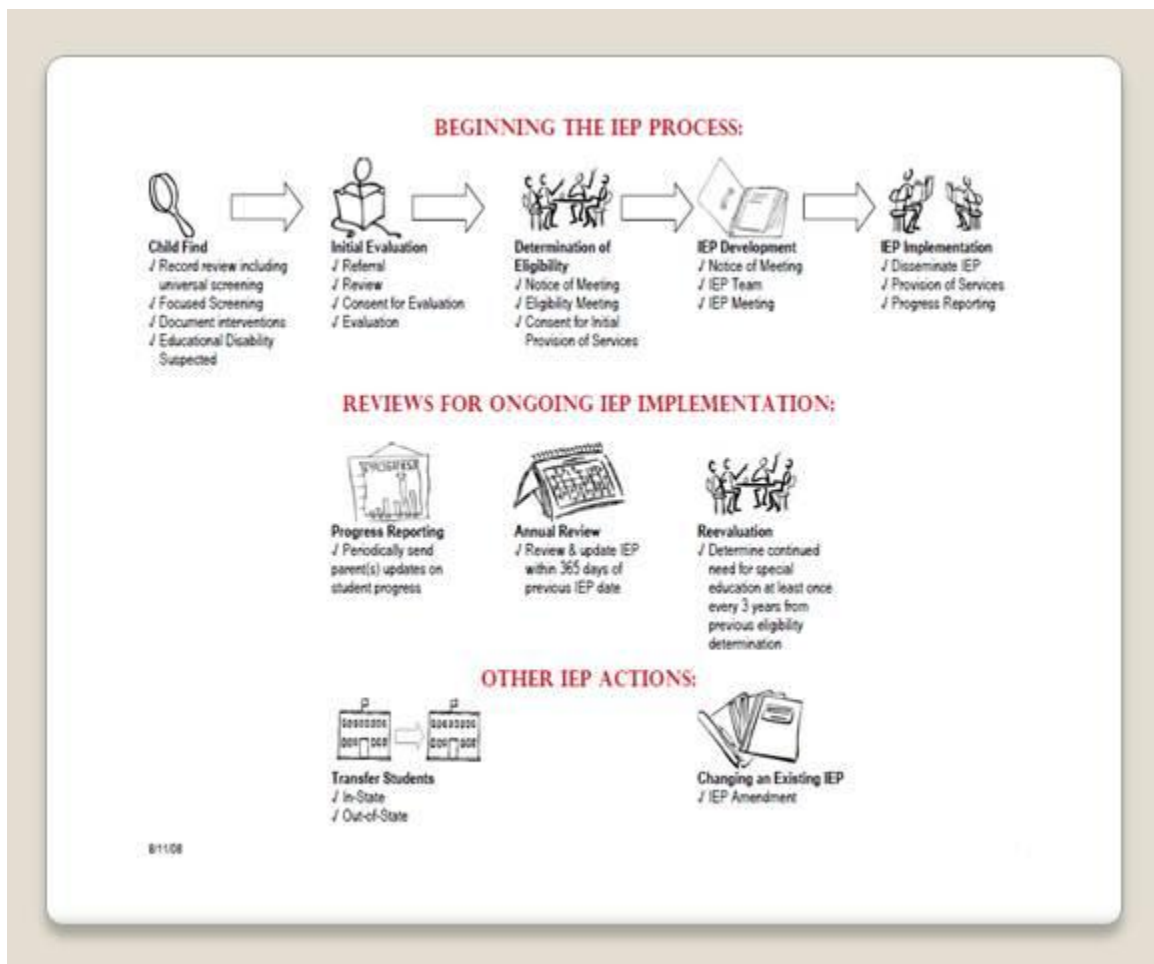
- **Differences Between IDEA and IDEIA**
- IDEIA clarified certain special education terms. IDEIA eliminated much of the paperwork burden and extended notification process teachers and school administration had to go through. Additional differences include allowances for non-English speaking students in need of additional English proficiencies as well as protection for parents from forced participation in educational interventions.

## **IDEA vs. IDEIA**

- **Differences Between IDEA and IDEIA**

- Although specific changes to verbiage and rules are numerous, the bulk of the differences between IDEA 1997 and IDEIA rest in the view with which Congress takes on special education. Primarily, IDEIA encourages cooperation between parents and school systems by reducing restrictions that limit resolutions outside of formal meetings or hearings. It also highlights the need for non-English speaking students and other students with particular needs to retain eligibility for special education without needing learning disability labels.

**IDEA vs. IDEIA**



Most of you have already been through the “beginning” stage of the IEP process. You are now in the “ongoing” stage where you will have annual reviews and reevaluations. Although you may have an idea of the process, you may not know specifically what should happen, what the options are, and what questions to ask. Perhaps after this session, you will be better equipped when you have your next IEP meeting. Remember, you are part of the team and are allowed to ask questions and should be educated on the specifics of the IEP process and documentation. It shouldn’t be a battle but a collaboration of ideas from ALL team members.

- Written notice is provided either when a special evaluation is proposed or if no additional evaluation data are needed
- Parent gives permission for an initial or special education evaluation
- Parent gives permission for reevaluation
  - The school can proceed without permission if the parent does not respond and if the school has made reasonable attempts to obtain permission

## **Prior Written Notice & Consent for Evaluation**

Permission is important. Don't simply say "yes" or "no". Find out what you are consenting, or not consenting to. Ask why certain evaluations are or are not being completed. If you don't feel comfortable with giving an answer, talk with your team and express your concerns.

- *"The date in which school receives the signed written consent for evaluation triggers both the 60 calendar-day timeline for the completion of the evaluation and the 90 calendar-day timeline for the development of the IEP"*

-Colorado Department of Education

## **Prior Written Notice & Consent for Evaluation**

- Notifies and invites the parents, guardians, or educational surrogates of any meeting regarding the identification, evaluation and/or provision of a free appropriate public education to his/her school
  - Parents are expected to be equal participants, along with school personnel, in developing, reviewing, and revising the IEP.
- If students are 14 or older, they receive a notice of meeting

## Notice of Meeting

Think about whether or not your adolescent should be part of the process. In most cases, the student should be involved. They are also part of the team and their voices should be heard.

- Identifies the type of meeting
- Gives demographic information of student and family
- Gives important upcoming dates such as the next annual and next triennial review

**Cover Page**

Make sure this information is correct...it is a legal document and should have the correct information.



- *"There are several important considerations that should inform the assessment process. First, a developmental perspective is critically important. While the core symptoms are present during early childhood, ASD is a life-long disability that affects the individual's adaptive functioning from childhood through adulthood. Evaluating the child within a developmental assessment framework provides us with a yardstick for understanding the severity and quality of delays or atypicality"*

*- A Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools*

## **Evaluation Reports**

Assessments should not be chosen based on what is available or what is given to every other student on an IEP. It should be individualized based on the needs, age, ability, language, and disability of the student. It should also yield relevant information that can help guide the next developmental steps.

- Evaluation data are used to make decisions such as determination of eligibility and to indicate appropriate services including goals, LRE, and accommodations

## **Evaluation Reports**

- According to the Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools, assessments should include:
  - Record review
  - Developmental and medical history
  - Medical screening and/or evaluation
  - Parent interview
  - Parent/teacher ratings of social competence
  - Direct child observation
  - Cognitive assessment
  - Academic assessment
  - Adaptive behavior assessment
  - Communication and language assessment

## Evaluation Reports

- **Direct Observations**

- Allows practitioners to gain qualitative data regarding a student's functioning in the school environment
- May use structured observation tools such as:
  - Autism Disorder Observation Scale (ADOS)
  - Childhood Autism Rating Scale (CARS)

## Evaluation Reports

Observational data can give great insight into the functional abilities of the student in a practical sense. Cognitive assessments don't always give the whole picture. Your child is not a number...they have abilities beyond the numbers. Observational data can help paint the whole picture.

- **Parent/Teacher Report**

- Allows the practitioner to obtain information from both the school and home environments to compare across settings
- Examples
  - Autism Diagnostic Interview (ADI-R)
  - Social Communication Questionnaire (SCQ)
  - Social Responsiveness Scale (SRS)

## **Evaluation Reports**

- **Achievement Assessments**

- Evaluates a student's ability in math, reading, and writing as compared to their same-aged peers
- Examples
  - Wechsler Individual Achievement Test, Second Edition (WIAT-II)
  - Woodcock Johnson, Third Edition (WJ-III)
  - Kaufman Test of Individual Achievement, Second Edition (KTEA-II)

## **Evaluation Reports**

- **Cognitive Assessments**

- Measures strengths and weaknesses of cognitive processing abilities such as memory, speed of processing, verbal and nonverbal reasoning
- Examples
  - Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV)
  - Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV)
  - Differential Ability Scales, Second Edition (DAS-II)
  - Cognitive Assessment System (CAS)

## Evaluation Reports

- **Communication Assessments**

- Measures speech language abilities such as vocabulary, syntax of language, speech rate, and understanding of nuances involved in everyday language
- Examples
  - Comprehensive Assessment of Spoken Language (CASL)
  - Pragmatic Language Skills Inventory (PLSI)
  - Test of Pragmatic Language (TOPL)

## Evaluation Reports



- **Adaptive Assessments**

- Measures level of independent functioning in the areas of self-care, social functioning, community safety, on the job functioning, and independent living

- **Examples**

- Vineland Adaptive Behavior Scale, Second Edition (VABS-II)
- Adaptive Behavior Assessment System, Second Edition (ABAS-II)
- Scales of Independent Behavior, Revised (SIB-R)

## **Evaluation Reports**

### **Other Domains Include:**

- Sensory Processing
- Executive Functioning
- Motor Skills
- Family System
- Coexisting Behavioral/Emotional Issues

### **Assessments:**

- Sensory Profile (SP)
- Behavior Rating Inventory of Executive Function (BRIEF)
- Test of Visual Motor Integration (VMI)
- Parenting Stress Inventory (PSI)
- Behavior Assessment Scales for Children, Second Edition (BASC-2)

## **Evaluation Reports**

- Difficulty generalizing
- Students with ASD can become prompt dependent meaning that if the prompts change from what they are used to, they may not perform as well
- Exhibits stimulus over-selectivity meaning students with ASD tend to focus on irrelevant stimuli instead of on the important aspect of a stimulus

## **Assessment Considerations**

- Poor response to change
- Students with ASD tend to have difficulty imagining themselves in different situations, which affects their response to test questions that ask them to do so
- This is why it is important to use multiple sources of information. Again, it is a process, not a single assessment.

## **Assessment Considerations**

### **IMPORTANT!!!!**

- An assessment by itself only tells part of the story. Be sure to look at all of the evaluations together to see the big picture.



### **Also....**

- Don't get stuck on "numbers". Again, look at the big picture. The numbers help guide services both in the school and in the community, but they, by themselves, don't explain the whole child.
- Your child is more than a number!

## **Evaluation Reports**

- But you are not done yet!



### **Determination of Eligibility**

Determines if a student has a disability and is eligible for special education.

**Be sure that sufficient testing has been done to make the best decisions for your child!**



- Eligibility for services related to an ASD require:
  - Sufficient evaluations have been completed
  - Should be documented that the child cannot receive reasonable benefit from general education alone
  - The performance is not due to lack instruction and is not due to limited English proficiency

### Eligibility in the Category of Autism

A specific category helps drive what services are put into place. If your child has been officially diagnosed with ASD, the Autism checklist will be used. If your child has not officially been diagnosed with an ASD but has many of the characteristics, the Other Physical checklist may be utilized. In the end, what matters is that your child meets eligibility criteria and that **appropriate** services are implemented based on **your** child's needs!

Be prepared to answer these questions. Don't take them lightly. If you get lost in the language, ask! It is important that this information is answered thoroughly and with complete understanding.



**"The student's Physical Disability in the area of Autism is characterized by: (All 3 of the following shall be documented)"**

- Qualitative impairment in social interactions; *and*
- Qualitative impairment in communication; *and*
- Restricted repetitive and stereotyped patterns of behavior, interests, and activities

**"The student's Physical Disability in the area of Autism interferes with: (check those that apply)"**

- Functional communication (verbal and nonverbal); *and/or*
- Social interactions and relationships; *and/or*
- Behavior; *and/or*
- Cognitive Processing; *and/or*
- Motor Skills; *and/or*
- Self-help/daily living skills

## **Category of Autism**

- Used to establish a baseline for which all goals can be measured against
- Documents concerns and ideas for enhancing the student's education
- Specific areas include:
  - Student strengths, preferences, and interests
  - Present levels of educational performance summary – Written for all relevant academic and non-academic areas in which the student requires specialized instruction
  - Identifies age-appropriate transition assessment processes used to identify post-school goals (to be discussed in more detail later)
  - Student needs and impact of disability

## **Present Levels of Academic Achievement and Functional Performance**

Strengths are just as important as areas of weakness. For children with autism related disorders, strides should be taken to build on their strengths as they may serve as areas of career development.

**This section is used to:**

- Consider any special factors that may interfere with the student's learning
- All areas must be considered by the IEP team

**Includes:**

- Learning Media Plan – for students who are visually impaired or deaf and blind
- Communication Plan – for students who are hearing impaired or deaf and blind
- Healthcare Plan
- Limited English Proficiency
- Assistive Technology
- Special Transportation

**Consideration of Special Factors**

- Identifies transition activities, for students 15 or older (or by the end of 9<sup>th</sup> grade), such as
  - Projected date of graduation or high school completion
  - Projected type of completion document

❖ *Note: Transitions will be discussed in greater detail in a later session*

## **Post-School Considerations**

- Indicates growth from the measurable present level of performance
- Reflects areas of need that are related to progress in the general education curriculum
- Must be measurable
- Describes conditions under which the student will perform

## Annual Goals

Don't check off on the goals until you have a chance to review them. Make sure that they fit with your child's needs, strengths, and future goals. Work with your team in the development of the goals.

**1. Student will develop social understanding skills as measured by the benchmarks listed below**

- Will work cooperatively with peers in small group settings
- Will develop an understanding of the relationship between his/her verbalizations and actions
- Will appropriately acknowledge an interaction initiated by others by giving appropriate response

**2. Student will increase perspective taking skills as measured by the benchmarks listed below**

- Will identify various emotional states in others 4 out of 5 times
- Will state why a person might be feeling a particular emotion 4 out of 5 times
- Will state what would be an appropriate emotional/behavioral response to specific social situations 4 out of 5 times

**Sample IEP Goals and Objectives for Students with ASD**

*A Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools*

- Modification = Changes made to instruction or the curriculum that fundamentally changes what the child is expected to learn. Examples of modifications include providing instruction to the child at a different academic level or testing him on different knowledge or skills than other students in the class.

## **Accommodations & Modifications**



- Accommodation = Supports that are provided to a child throughout the school day that do not significantly alter what is being taught or how the child participates in school activities. Examples of accommodations are preferential seating, extended time on tests, daily communication logs to share information between school and home, use of spell check an/or computer, enlarged print, and books on tape.

*-Negotiating the Special Education Maze,  
Fourth Edition: A Guide for Parents and  
Teachers*

Winifred Anderson, Stephen Chitwood,  
Deidre Hayden & Cherie Takemoto

## **Accommodations & Modifications**

Be careful not to add too many accommodations. Too much of a good thing can be harmful. Some children become too dependent on their accommodations and may not be able to learn how to deal with challenges and independence. Be thoughtful and considerate of all factors when asking for accommodations and modifications. It's okay for your child to struggle...it leads to learning!



### **Extended School Year (ESY)**

- Consider whether the student needs extended school year services in order to receive FAPE
- Need to think about early in the year in order to establish and test against a baseline

### **State/District Assessments**

- Consider the student's participation in local and statewide assessments of academic performance
- Need to discuss accommodations on such tests. These accommodations need to be in place three months prior to the assessment date

## **IEP Basics**

- Identify areas of the curriculum and the student's development that require specialized instruction or intervention from a special education teacher and/or related service provider

**Special Education and Related Services in the Least Restrictive Environment (LRE)**

Consider factors such as services versus time spent with “typical” peers. For adolescents, the modeling they receive from their peers can be more impactful than the time they have with the OT to work on handwriting.

- **Ages 6-21**

- Percentage of time inside the general education classroom. Includes time spent in age-appropriate community-based settings that include individuals with and without disabilities (e.g., college campuses, vocational sites)

- Categories include:

- 80% or more
    - No more than 79%
    - Less than 40%
    - Separate School
    - Residential Facility
    - Homebound
    - Correctional Facility

**LRE**

- Some students, whose behavior impedes their or other's learning, may require a BIP
- Indicates positive behavior interventions to support and address issues related to undesirable behaviors
- Developed through the use of a Functional Behavior Assessment (FBA)

## **Behavior Intervention Plan (BIP)**

Not all behaviors related to ASD can be “fixed” through any intervention. They can be better understood and perhaps minimized by developing and BIP. It is important to note that this is different than a behavior contract. It is not what your child is going to do to change behavior. Rather what can the team do to teach more appropriate behaviors and what are the options in case the behaviors become worse. It has nothing to do with discipline.

- FBA's include observations, interviews, and other tools to generate hypotheses regarding the motivation behind the problematic behavior; and a description of the behavior and its reinforcing consequences that increase the likelihood of it happening.

## **Functional Behavior Assessments (FBA)**

- Should include:
  - Setting Event Strategies – strategies designed to prevent or reduce the occurrence of the unwanted behavior
  - Antecedent Strategies – preventative strategies to address the triggering events
  - Behavior Teaching Strategies – designed to replace problematic behaviors with more desirable and acceptable behaviors
  - Reinforcement Strategies – strategies designed to make the problem behavior less effective

## **Behavior Intervention Plan**

- Should include:
  - Crisis Intervention Plan – if the behaviors become unsafe, there needs to be a plan to reduce harm to self and others
  - Ongoing evaluation
  - Contextual fit – Must fit the environment where it is to be implemented
  - Communication Plan – How all parties are notified of the plan

## **Behavior Intervention Plan**



## \* Session 3: The Teen Years

Puberty, Relationships, Sexuality, and  
other Teen Issues

The topic of puberty, relationships, and especially sexuality can be very difficult for any parent. It brings about anxiety when we think of our children as sexual beings (remember the techniques from last week to reduce your anxiety!) and to admit that they are growing up. Although puberty is relatively the same for all kids, the parents of neurotypical children have it easy compared to parents of children on the spectrum. Why? Because they can use metaphors like, “the birds and the bees,” or innuendoes such as “rolling in the hay”. Kids on the spectrum may take these statements literally and will not fully understand what is being discussed. In the book, *Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between*, the author of the chapter on this topic, Isabelle Henault, explains why this is particularly difficult for parents of children on the spectrum.



*For the majority of Aspies, sexual behaviours are perceived as any other behavior, free of social rules and convention. In contrast, parents and professionals often view sexuality in a very different manner. For them, sexuality may be taboo, value laden and a source of malaise. The need to protect the adolescent may be so strong that the subject of sexuality is avoided or banned altogether. There is also a tendency to define everything with respect to AS. This perspective fails to consider that adolescence, as a developmental period, brings about a variety of changes, new behaviours, and a need for discovery.*

*Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between*

\*Hanault goes on to say that the danger in avoiding these conversations can actually increase the likelihood that an adolescent will act out inappropriately. For the parent of a child on the spectrum however, there are many complexities that need to be accounted for when explaining the topics of puberty, sex, and relationships.



\***Don't Avoid the  
Difficult  
Conversations**



# \*PUBERTY

It's a process, not an event!

- \* Don't make assumptions regarding the level of knowledge a teen on the spectrum has regarding these issues
- \* Those on the spectrum may not be able to learn about such issues by imitating their peers
- \* These topics need to be discussed intentionally, concretely and at a level your teen can understand

\* *Adolescents on the Autism Spectrum*  
by Chantal Sicile-Kira

Because children on the spectrum are not comfortable with change, it is important to prepare them for what changes puberty will bring. Sicile-Kira suggests that the following facts be considered when preparing the teen for the changes they are about to encounter:

- \*Your child's emotional maturity level
  - \*Your philosophical and religious beliefs
  - \*Whether or not these areas will be addressed at home, at school, or both
  - \*His/her method of communication and learning style
- \* Guidelines as to what, where, how and when to teach these topics to your teen**

Because children on the spectrum are not comfortable with change, it is important to prepare them for what changes puberty will bring. Sicile-Kira suggests that the following facts be considered when preparing the teen for the changes they are about the encounter:

- \* Your child's chronological age
- \* What he has already been taught
- \* Your child's maturity level
- \* Whether or not your child is fully integrated at school
- \* The level of understanding your teen demonstrates as well as his/her functional abilities

\* **Guidelines as to what, where, how and when to teach these topics to your teen**

### Hygiene

- \*This needs to be addressed or readdressed due to the onset of sweat, acne, the need to shave and, for girls, the use of feminine hygiene products

### Seizure Activity

- \* According to Sicile-Kira, seizure activity begins during puberty for 25% of individuals with ASD. This could be due to changes in hormones and may not be noticeable. Signs to look for that may necessitate medical advice include sudden drop in academic gains, the loss of behavioral and/or cognitive gains, or the onset of problematic behavior such as self-injury, aggression, or severe tantruming.

\*FACTS



\* Puberty in boys - This usually starts around age 10 to 11 and continues until about the age of 20. This involves the production of testosterone, which then promotes hair growth on the face, legs and genitals. They may experience new body odors from an increase in sweating. And, they will have growth spurts, develop muscles, have a deepening of the voice, and experience growth of the penis and testicles. Boys should be taught about erections, “wet dreams”, and ejaculation. Although difficult, this needs to be discussed to avoid inappropriate preoccupation, or fear regarding these changes.



\* **FACTS**





## \*FACTS

\* Puberty in girls - Girls often start puberty before boys, sometimes at the age of 8 or 9. The growth in height, weight, and breast size continues until the age of 16. Often, they may have their first period by the age of 11 or 12. However, girls develop at different rates. Sicile-Kira suggests discussing the menstrual cycle with girls prior to their first period to avoid confusion and fear. It is also important to identify safe people to discuss this with and to give them specific information on how to use sanitary pads.

\*Behavioral problems -  
Some children who struggle with aggression and physical acting out may actually calm down during puberty. However, some teens begin to act out more often. This may be due to factors such as boredom, hormonal changes, or teenage “rebellion”.

\*Precocious puberty -  
This has been estimated to be 20 times higher in children with ASD. Watch for the signs and if you have concerns, contact your medical provider.

\*FACTS

\*Physical maturity vs. Emotional maturity -  
Although children with ASD physically mature at the same rate as their neurotypical peers, they may lag behind in regards to their emotional maturity. Instead of showing interest in the opposite sex, more independence, and in risk taking behaviors, teens with ASD may continue to show interest in more immature topics.

\*FACTS

\*Mental health issues - Some teens with ASD become aware of their “differences” during these years. This can result in anxiety and depression. This is the time when teaching your teen to talk about these feelings is important. Sicile-Kira recommends pictures or simple drawings for those who may be nonverbal or unable to express verbally what they are feeling. Depression in teens with ASD should be taken seriously due to possible biological predispositions to the condition and suicidal ideation should not be ignored!

\*FACTS

## \*Time to REFLECT

*Keep it Simple!*

*How might you talk with your child about puberty and the changes that are on the horizon?*

*Are you comfortable discussing these difficult topics with your child?*

*Take a few minutes to think about what you might say and what you may not be able to say. Write down some ideas and what some of the hang-ups might be.*





## \* Relationships and Sexuality

After the process of puberty begins, parents may notice some additional changes with their teen regarding relationships and sexuality. The changes are more behavioral and can include looking at pictures of members of the opposite sex either in magazines or online; they may engage in masturbation which needs to be explained as a “private” activity; they may say things that are more sexually charged; and they may become more “touchy” with members of the opposite sex. All of these things are normal, even for neurotypical teens, but need to be discussed, especially with teens on the spectrum. Although teens will learn some of the information from school, it is important that they also hear from you. This is important so that your philosophies, religious perspectives, and/or moral expectations can be infused in what you teach. This can be a very difficult conversation to have. It can be even more difficult for the parent of a teen on the spectrum because of how direct it needs to be. Teens on the spectrum don’t learn through abstract language so the use of innuendoes can leave them more confused. You need to be direct, concrete and factual. Because this can be difficult, here are some helpful pointers. These come from the book *Autism, Asperger's & Sexuality: Puberty and Beyond* written by Jerry and Mary Newport, a married couple who are both on the spectrum and have a unique perspective of the topic.



- \* It's ok to start the conversations with your teen, even if it seems too early. If you wait until it is absolutely necessary, it may be too late.
- \* Find a comfortable place to have this discussion and have the discussion often. It is a life-long process that allows for open communication.
- \* Begin by asking what they do know but correct them with facts in a non-condescending manner.
- \* Find age-appropriate literature that you feel is at your teen's level of understanding. Books that come from a scientific perspective may be easier to understand.

## \*Talking about Sex

- \* Use pictures from a manual to describe and explain the functions of sexual parts, both male and female.

- \* Discuss that sex is a part of growing up and is acceptable as a topic of discussion at the proper time and place.

- \* Discuss the responsibility for one's actions in seeking and having sex.

- \* Discuss the importance of respecting the wishes of possible sexual partners. This may be a good time to talk about the fact that not all romantic interests will be sexual partners. They can go on dates or go to dances with members of the opposite sex but that does not mean they will be having sex.

## \* Talking about Sex



\* Sexual drives have to be moderated by responsibility. For some teens, this may simply mean not touching others, not staring, or not hugging every boy or girl they see. For others this may mean restricting internet access and monitoring text messages.

\* Discuss hygiene, birth control and disease prevention. You may need assistance from a medical professional who knows your teen well especially if you are considering medication as a means of birth control.

## \*Talking about Sex

\*Talk about the feeling of being left out because of the lack of social participation. For girls this may mean that sex should not be used as a way to gain attention or popularity.

\*Reinforce the fact that you are there for them to discuss anything that may come up.

\*Explain the idea of “locker room tales” and that many of them are false.

\*Talk about your experiences with dating and social life.

## \*Talking about Sex

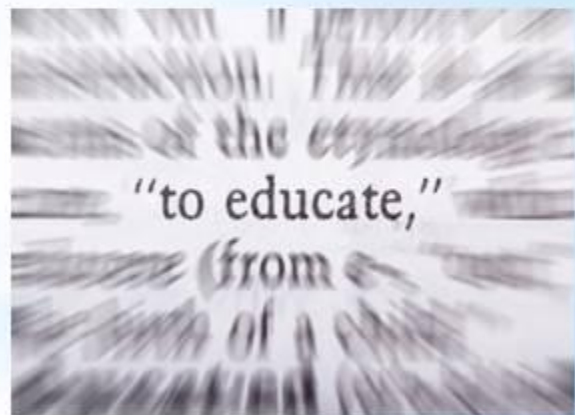
\*For some teens, you may need to enlist the help of teachers and paraprofessionals to help monitor behavior. For the teen who cannot express their sexual frustrations and cannot ask questions, they may show more aggressive behaviors. Physical activities can sometimes alleviate these frustrations.



\*Talking about  
Sex

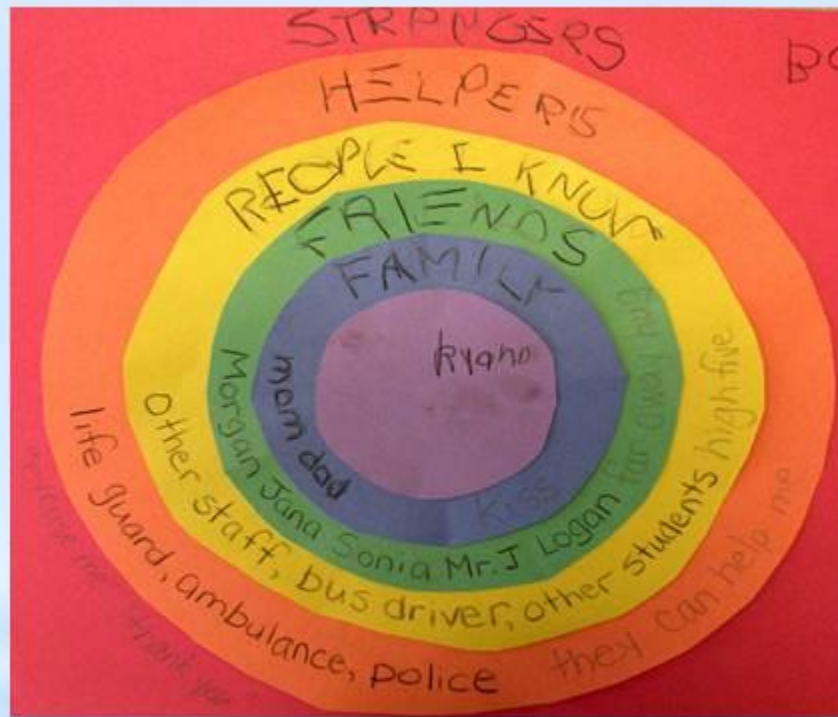
*\*Growing up on  
the Spectrum  
by Dr. Koegel*

Although there is not  
a lot of research on  
the ASD population  
and sex, there are  
specific areas that  
should be addressed



\*Talk about when it is ok to touch another person and when it becomes offensive. If your teen already struggles with personal space, start working on it directly before it becomes a problem. You don't want to punish, you just want to make the rules clear and understandable. You can break it down so it easy to understand such as, "Hugging is good for relatives and adult friends, but shake hands with new acquaintances." If your teen is visual, Dr. Koegel recommends drawing some social circles or write a list and discuss appropriate touching

 **Inappropriate  
Touching**



## \*Social Circle



\* Because some kids on the spectrum become fixated, this can be a real issue. Although harm is not intended, objects of interest can understandably become uncomfortable. One way to alleviate this is to involve your teen in other activities and to meet new people. This can get their mind off of the person of intense interest. It is important for you as a parent and for the professionals who work with your teen to understand that the intent is to gain a friend or romantic interest so creating other opportunities to meet people should be effective. Simply telling them to stop will not work.

## \* Stalking

\* Many kids on the spectrum are oblivious to matters of modesty and parents need to be explicit and detailed in discussing this area. Dr. Koegel recommends that you buy clothes that naturally preserve modesty such as pants instead of dresses. Teaching teens routines such as checking tampons or checking zippers, in private, can be helpful.

\* **Modesty**



\* Because kids with ASD lack social awareness, distinguishing between what is a public activity versus what is a private activity can be difficult. Again, explicit and detailed information is necessary.



## \* Private vs. Public

\* Individuals with disabilities are often victims of abuse. Teaching your teen about personal boundaries in very clear, specific terms can be helpful. Be precise about what is OK and not OK and with whom they may have relationships. If your teen is nonverbal, frequently check on the people he/she spends time with including teachers and paraprofessionals.

## \* Abuse Prevention



# \*Bullying

Advice from the Experts

\* *"The secondary school that I went to had a very good reputation and in particular a good reputation where bullying was concerned. That's why my Mum fought so hard to get us in. For me it didn't work out. The bullies there just couldn't be dealt with and no amount of threatening by my brother, by the teachers, the fear of expulsion, pleasant reasoning, absolutely nothing made any difference and they never left me alone. In the end they were physically pushing me around and punching me and it was about the worst time of my entire life"*

\* *Freaks, Geeks & Asperger  
Syndrome: A User Guide to  
Adolescence*

*by Luke Jackson (13-year-old with Asperger Syndrome)*

\* *“If you are asking your child about bullying, then be specific in your questions. You will need to ask if anyone has been pushing or shoving them, upsetting them and being nasty to them or hitting or kicking them. Even then you may not ask the right question so be aware of that”*

## \* Luke's Advice to Parents

\* *“Remember that, as I have said earlier, bullies don’t actually say, ‘Now I am going to bully you.’ Therefore, your child may not realize that the torment they are suffering is bullying”*

## \* Luke’s Advice to Parents

\**“One thing that parents should not do is go into school and confront the bullies in front of everyone. All that happens there is that everyone laughs and calls you a baby and a Mummy’s boy and it generally gets even worse”*

## \***Luke’s Advice to Parents**

*\*“If you are going to talk to the teachers about your child’s bullying, do this in private too. Don’t take them into school in the morning and then stop and talk to the teacher. It’s not very nice to sit in a class and know that your are being talked about”*

## *\*Luke’s Advice to Parents*



\**“When you know that your child is being bullied and you still send them in to school, you are throwing them into a den of lions. It is your job to protect your child so go to any lengths possible to do so”*

## \***Luke’s Advice to Parents**

*\*“If it isn’t sorted satisfactorily, then please, please, please take your child out of school till it is. Don’t make them suffer whilst you try and sort it”*

## *\*Luke’s Advice to Parents*

\* *"On the way to my son's locker he told me, 'Mom I want to die. Nobody likes me.' My heart broke for him. Yes, I know. A lot of normal Junior High School kids express these same feelings during these difficult years, but this was my autistic son, a young man who gets upset when I kill a fly in the house instead of escorting it out the door. He had been harassed to the point of punching someone and now wanting to die"*

\* *Talking Teenagers: Information and Inspiration for Parents and Teenagers with Autism or Asperger's Syndrome  
by Ann Boushey*

\**“Sheila Wagner, Assistant Director at the Emory Autism Center in Atlanta, writes about how to support an autistic student who is being bullied: ‘Accept that bullying occurs, believe the student with AS, make sure they have at least one supportive friend and teacher they can count on, teach skills that can deflect bullying, do not have proximity to bullies and have real consequences for the bullies’ (Wagner 2004, p. 25)”*

## \* Ann’s Advice to Parents

\*There are people who can and are willing to help your son or daughter. Be sure to form relationships with teachers, deans, psychologists, or whomever you feel comfortable with. If you don't feel you are being supported, go to someone else. Talk about your concerns. Above all else, make sure that your son or daughter has a safe person at school that they can go to in case of emergencies.

\*There is Good News:)

### **NO QUESTIONS ASKED PASS**

Please allow Luke to take a 5 minute cool-down walk with no questions asked. If that is not sufficient, please allow him to come to Mr. Smith's office for further assistance.

## **RED CARD**

\*“According to HB 11-1254, “Bullying” means any written or verbal expression, or physical or electronic or gesture, or pattern thereof, that is intended to coerce, intimidate, or cause any physical, mental, or emotional harm to any student. “Bullying” is prohibited against any student for any reason, including but not limited to any such behavior that is directed toward a student on the basis of his or her academic performance; or against whom federal and state laws prohibit discrimination upon any of the basis described in section 22-32-109 (1)(11)(l).”  
(<http://www.cde.state.co.us/pbis/Bullying/index.htm>)

\*Colorado  
Department of  
Education



\* “As of November 15 per HB 11-1254, the CDE will be soliciting schools and districts to submit evidence-based practices, strategies, and programs that address preventing and intervening with bullying behaviors.”

\* **Colorado**  
**Department of**  
**Education**





## TRANSITION TO ADULTHOOD



As difficult as it is to imagine, your child is growing up and will, in a few short years, be an adult. You and your child have faced many challenges. The transition to adulthood is just another hurdle full of uncertainty and fear. However, with careful planning, this transition will be a challenge that you and your child can face confidently and successfully, just as with every other challenge you have faced thus far. This session includes a handful of tips to get you thinking about the next step in your journey. They are no means exhaustive but will hopefully provide you with starting point.

# WHAT IS TRANSITION TO ADULTHOOD?

- ▶ What does this mean to you?
- ▶ What steps have you and/or your IEP team taken to prepare for this next developmental step?
- ▶ What fears do you have?



## ISSUES TO CONSIDER

- ▶ Education
- ▶ Employment
- ▶ Independent Living
- ▶ Social/recreation
- ▶ Legal Issues



## IDEA 2004

- ▶ The term “transition services” means a coordinated set of activities for a child with a disability that:
- ▶ Is designed to be within a result-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
- ▶ Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and
- ▶ Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]

# TRANSITION ASSESSMENT

- ▶ *“The purpose of transition assessment is to assist the team in identifying priorities and developing a transition IEP. The development of a sound, comprehensive transition IEP that leads to employment or postsecondary education options for students with disabilities is one of the **most important** activities that middle and high school teams can do for students with autism”*

*-Autism & the Transition to Adulthood: Success Beyond Classroom*

*Rae Whitman, Maria Danner Smith & Carol Schall*

# TRANSITION ASSESSMENT

## ► Colorado Department of Education –

- When a student is 15 or in the 9<sup>th</sup> grade (can talk about sooner) an age appropriate, transition focused assessment process must be used to identify post-school goals. This ongoing process includes both formal and informal methods of gathering data related to the student's interests, preferences, aptitudes and abilities as they relate to an align with the skills needed for the student's given interest area.

# TRANSITION ASSESSMENT

- ▶ Considers:
  - ▶ Future employment,
  - ▶ Education,
  - ▶ Independent Living, and
  - ▶ Personal and social environments.
- ▶ It is **NOT** a single assessment.
- ▶ It **IS** a process.



# TRANSITION ASSESSMENT

- ▶ Must come from multiple sources
  - ▶ Shift from what is missing in a student's developmental profile to what skills are necessary for the student to be successful
  - ▶ Describe supports and modifications necessary for the student to be successful in the future.
- ▶ **Includes:**
    - ▶ Interests,
    - ▶ Preferences,
    - ▶ Strengths, and
    - ▶ Work habits describe supports and modifications necessary for the student to be successful in the future.



# TRANSITION ASSESSMENT

- ▶ Sitling and Clark (2007) identified eight areas that compose minimum compliance with the charge to assess academic and functional performance
- ▶ Interests
- ▶ Preferences
- ▶ Cognitive development and academic achievement performance
- ▶ Adaptive behavior
- ▶ Interpersonal relationship skills
- ▶ Emotional development and mental health
- ▶ Employability and community skills
- ▶ Community participation

## TRANSITION ASSESSMENT

- ▶ Wehman, Smith and Schall propose the following questions be part of the discussion prior to or as students enter high school:
- ▶ To what degree is the student self-determined, that is able to make personal decisions and accept responsibility for those decisions?
- ▶ What is the student's or caregiver's vision for the student's future?
- ▶ Where does the student want to live and work as an adult?

## TRANSITION QUESTIONS CONTINUED:

- ▶ What elements would create an enviable life for this student?
- ▶ What skills and abilities does the student currently possess that would match his or her vision?
- ▶ Will this student need additional training or education after high school to be able to realize his or her vision?
- ▶ What resources are available to the student to help him or her achieve this vision?
- ▶ Is this student able to live independently, that is, does the student have the ability to care for him or herself, live independently in an apartment or a house, get around in the community, and/or budget money wisely?

## TRANSITION QUESTIONS CONTINUED:

- ▶ What is the depth of this student's experiences in the world of work and adult life?
- ▶ What skills and abilities will this student need to better inform his or her decision making to prepare for life beyond high school?
- ▶ What experiences, resources, and new agencies will increase the likelihood of a smooth transition into work or postsecondary education and adult life?



# TRANSITION ASSESSMENT

- ▶ The authors go on to say that the following assessments then be used to help guide further decisions:
- ▶ Career Awareness Assessment – collecting this information will assist the team in identifying the types of career awareness experiences a student needs in order to make decision about desired jobs or postsecondary education
- ▶ Vocational Evaluation and Assessment – to identify a student's employability and vocational skills and to identify potential job matches. Important to use more natural methods of evaluation such as performance samples, behavioral observations, and situational assessments
- ▶ Assessment of Self-Determination – ability to make choices, select goals, and develop a plan to achieve those goals

## PERSON CENTERED PLAN

- ▶ Also known as Personal Futures Planning, this tool is helpful in creating and illustrating an action plan for the next stage in life.
- ▶ Compares the “vision” to current events
- ▶ This plan acts as a guide for future planning



## Considering Employment?

Supported Employment either through adult agencies or the high school. Services possibly offered

Group placement model – full time instructor works with small group in an integrated employment setting

Mobile Crew – Small group goes to a variety of community job sites





## CONSIDERING EMPLOYMENT?

- ▶ Career fairs and job tours through communities, high schools, or colleges
- ▶ Job Shadowing and internships
- ▶ Entrepreneurial business model – private business employs students with disabilities
- ▶ Department of Vocational Rehabilitation – federal and state funded program to assist individuals to identify employment goals, and to obtain education, training and other supports to become employed. Should apply no later than the beginning of your child's junior year.

**Dr. Rick Blumberg**

*Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger's Syndrome*



## WHAT WOULD YOU LIKE IN A JOB

- ▶ Start by asking yourself a series of questions about how you like to spend your time, your day, your work time.
  - ▶ What does your perfect job look like?
  - ▶ What does your ideal day look like?
- ▶ To Find out, Brainstorm a checklist of your job criteria.
  - ▶ What do you need in your ideal job?
  - ▶ Is variety important to you, or would you rather have the same tasks each day?
  - ▶ Would you rather work in a more structured environment, or is an informal, somewhat free-flowing schedule better for you?
  - ▶ Do you prefer to work alone or with others?
  - ▶ Do you want to manage projects?

# WHAT WOULD YOU LIKE IN A JOB

- ▶ **Think about what is negotiable and not negotiable about your job.**

- ▶ How much money do you need to make to pay your bills, support yourself?
- ▶ Are your hours negotiable?
- ▶ Are you able to travel for work?

- ▶ *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism*

- ▶ Temple Grandin and Kate Duffy

# **JOBSTHATWOULD FIT....**

## **Visual Thinkers**

- ▶ Architectural and engineering drafter
- ▶ Photographer
- ▶ Landscape designer
- ▶ Graphic artist
- ▶ Heating, ventilation and air conditioning technician
- ▶ Web designer
- ▶ Veterinary technician
- ▶ Computer troubleshooter

## **Music/Math Brains**

- ▶ Computer programmer
- ▶ Engineer
- ▶ Physicist
- ▶ Musician/Composer
- ▶ Statistician
- ▶ Music teacher
- ▶ Electrician

## JOBSTHATWOULDFIT...

### Nonvisual Thinkers with More Verbal Brains

- ▶ Journalist
- ▶ Translator
- ▶ Librarian
- ▶ Accountant
- ▶ Bookkeeper and record keeper
- ▶ Special education teacher
- ▶ Speech therapist
- ▶ Bank teller



## JOBS THAT ARE TYPICALLY A “BAD FIT”

- ▶ Cashier at a busy store
- ▶ Waiter in a busy restaurant
- ▶ Receptionist
- ▶ Nurse in a busy hospital
- ▶ Manager in busy organization
- ▶ Bartender
- ▶ Police officer
- ▶ Pharmacist in busy drugstore
- ▶ Doctor in a busy clinic
- ▶ Casino worker
- ▶ Desk clerk in a busy hotel

## “BEST JOBS”....

- ▶ Aircraft Mechanic
- ▶ Artist
- ▶ College Professor
- ▶ Computer Programmer
- ▶ Drafting
- ▶ Engineering
- ▶ Accounting
- ▶ Graphic Arts and Design
- ▶ HVAC (Heating,Ventilation,Air Conditioning)

## “BEST JOBS”...

- ▶ Information Technology
- ▶ Learning Specialist
- ▶ Library Jobs
- ▶ Printing
- ▶ Biological and Medical Research Scientist
- ▶ Translator
- ▶ Veterinary Assistant and Technician

## WHAT ABOUT COLLEGE?

- ▶ Dr. Blumberg suggests the following:
- ▶ By age 15: Transition statement should include preference to attend college or not, and course and sequence that provide opportunity to do so should be laid out
- ▶ By end of 9<sup>th</sup> grade: Review whether college is still part of the vision. Does the student understand their IEP? Consider requests for PLAN accommodations if needed.



## WHAT ABOUT COLLEGE?

- ▶ Selecting a college?  
Consider:
  - ▶ Course of study
  - ▶ Location
  - ▶ Admission requirements
  - ▶ Cost
  - ▶ Campus life
  - ▶ Disability services



## WHAT ABOUT COLLEGE



- ▶ Consider making a post-secondary profile that includes:
  - ▶ Child study team records including evaluation reports and copies of IEP
  - ▶ Copy of WAIS or other cognitive assessment
  - ▶ Functional vocational assessment
  - ▶ Transcripts
  - ▶ Extracurricular activities
  - ▶ Best academic work
  - ▶ Timeline if thinking about college

## SUPPORTS FOR COLLEGE

- ▶ **Section 504** – This document, which is governed by the Americans with Disabilities Act (ADA), is designed to ensure that post-secondary programs do not discriminate against students on the basis of a disability. Requires any program (including college) that receives federal funding to provide accommodations for qualified students. Most colleges receive federal funding. If you can document that your child has a disability and that they are otherwise qualified to attend the program, the program must provide reasonable accommodations. Or the supports that will enable them to succeed. Reasonable accommodations include testing accommodations, adaptive tech, other supports such as interpreters, note-takers, scribes and readers.

## RESIDENTIAL SUPPORTS

- ▶ [www.Disabilityresources.org/DD.html](http://www.Disabilityresources.org/DD.html)
- ▶ State office typically provides fund to pay for residential services such as:
- ▶ Group homes
- ▶ Supervised apartments
- ▶ Foster homes
- ▶ Other supported living programs



## INCOME SUPPORTS

- ▶ Income supports – Start researching during 9<sup>th</sup> grade year
- ▶ Supplemental Security Income – SSI
- ▶ Social Security Disability Insurance - SSDI
- ▶ Social Security Administration  
[www.socialsecurity.gov](http://www.socialsecurity.gov)



## SUPPLEMENTAL SECURITY INCOME - SSI

- Benefits may be paid to persons who have a documented disability and who have little or no income. SSI provides for basic needs such as food, clothing and shelter. Individuals who are over 18 are considered eligible for SSI if they have a medically determined physical or mental impairment that precludes “substantial gainful activity”. Once your child turns 18, your family income is not taken into account.

## SOCIAL SECURITY DISABILITY INSURANCE - SSDI

- Income assistance program that provides cash payments to individuals who have a disability. To be eligible, a person must have worked and paid taxes for about five years, or be the adult child of a person who has worked and paid taxes.



## PLANNING FOR THE INEVITABLE

- ▶ A plan must be made for a child with a disability, even if it is only the realization that because you are not setting up a trust or putting a plan in writing, if something should happen to you, the state will take over the care of your child.
- ▶ In setting up a trust, do shop around and find an attorney who has worked with Medicaid and guardianship conservatorship issues.
- ▶ A limited guardianship/conservatorship at the age of 18 is not such a scary beast. Once you think about it, it really is just a continuation of the IEP you wrote and implemented for your child every year he/she was in school.

Ann Boushey, author of *Talking Teenagers: Information and Inspiration for Parents of Teenagers with Autism or Asperger's Syndrome* wrote a chapter about Planning for Our Own Demise. She spoke to a lawyer and this is what she came away with.



## PLANNING FOR THE INEVITABLE

- ▶ Setting up a living trust for Jon (Ann's son) is to enhance his life and give him the extras he may need to live his life, not to make him ineligible for the services he is entitled to. A careful attorney needs to watch for this
- ▶ Putting in writing that my sister or my husband's brother will be guardian in case something should happen to both of us may not be enough. It's time to talk to my son's older cousins and find the right one to do the job if necessary. This too needs to be in writing.
- ▶ Planning for my own death may be depressing, but so have been many things in my life such as the first IEP meeting I ever attended and several meetings thereafter.

## PLANNING FOR THE INEVITABLE



- ▶ *“This meeting with Don (attorney) brought it home in every intimate detail, that Jon is not normal, he has a disability. And I can’t let my guard down a minute, not even in death”*

*-Ann Boushey*